



Raising Children  
with Special  
Health Care Needs  
Complete Care Notebook



## Raising Children with Special Health Care Needs Complete Care Notebook

The Division of Family Health recognizes the role of families as partners with professionals in the health care of their children. Families are the most important care providers and advocates for their children, and our goal is to assist them in this role. The Division's Office of Families Raising Children with Special Health Care Needs is dedicated to providing families of children with special needs with support, guidance, and encouragement regarding the health care of their child.

This *Complete Care Notebook* was created in response to requests from families for a portable organizer to record and file their child's important health information, from birth through adulthood. The *Complete Care Notebook* allows families to easily access information about their child's emergency treatment, health history, care plan, care providers, support resources, and other important information.

We look forward to helping both parents and professionals take advantage of this new tool. If you have any questions or comments about this *Complete Care Notebook*, please let us know so that we may better support families in the future. Call the Family Health Information Line at 1-800-942-7434.

# Complete Care Notebook

## 1. Introduction

THIS COMPLETE CARE NOTEBOOK BELONGS TO / PHOTO PAGE	1.1
HOW TO USE THE COMPLETE CARE NOTEBOOK	1.2

## 2. Emergency Information

ABOUT THIS SECTION	2.1
CHILD'S EMERGENCY MEDICAL INFORMATION	2.3
FAMILY'S INFORMATION	2.5
MEDICAL INSURANCE	2.6

## 3. Health History

ABOUT THIS SECTION	3.1
MOTHER'S PREGNANCY HISTORY	3.3
CHILD'S BIRTH HISTORY	3.4
FAMILY MEDICAL HISTORY	3.5
CHILD'S DIAGNOSIS	3.6
CHILD'S FEEDING HISTORY	3.7
CHILD'S DEVELOPMENT HISTORY	3.9

## 4. Care Team Contact List

ABOUT THIS SECTION	4.1
PRIMARY CARE PHYSICIAN AND SPECIALISTS	4.3
PHARMACIES / MEDICAL SUPPLIERS	4.4
HOME CARE PROVIDERS	4.5
RESPIRE CARE PROVIDERS	4.6
CHILD CARE PROVIDERS	4.7
COMMUNITY RESOURCES AND REFERRALS	4.8

## 5. Health Tracking

ABOUT THIS SECTION	5.1
HEALTH TRACKING ADVICE	5.3
PHONE CONVERSATIONS AND VISITS WITH DOCTORS	5.7
TEST RESULTS	5.8
HOSPITALIZATIONS AND SURGERIES	5.9
HOSPITAL DISCHARGE PLANNING	5.10
MEDICATIONS	5.11
TREATMENTS	5.12
SEIZURE ACTIVITY FORM	5.13

## 5. Health Tracking (continued)

MEDICAL EQUIPMENT AND SUPPLIES	5.14
ALLERGY RECORD	5.15
DENTAL CARE RECORD	5.16
GROWTH TRACKING FORM	5.17
DAILY DIET TRACKING FORM	5.18
CALENDAR	5.19

## 6. Daily Routine

ABOUT THIS SECTION	6.1
HOME-BASED MEDICAL HEALTHCARE SCHEDULE	6.3
GETTING TO KNOW MY CHILD	6.4

## 7. Education Plan

ABOUT THIS SECTION	7.1
EDUCATION RECORD	7.3
EARLY INTERVENTION AND SPECIAL EDUCATION	7.4

## 8. Expense Tracking

ABOUT THIS SECTION	8.1
MEDICAL EXPENSE LOG	8.3
TRAVEL EXPENSE LOG	8.4

## 9. Resources

ABOUT THIS SECTION	9.1
FAMILY VOICES RESOURCE GUIDE FOR FAMILIES OF CHILDREN WITH SPECIAL NEEDS	

## 10. Glossary

HEALTH CARE DEFINITIONS	10.1
HELPFUL ACRONYMS FOR FAMILIES OF CHILDREN WITH SPECIAL NEEDS	10.5



+



PHOTOGRAPH  
OF CHILD

+

# Complete Care Notebook

This Complete Care Notebook Belongs To:

CHILD'S NAME

DATE OF BIRTH

TIME OF BIRTH

HOSPITAL WHERE CHILD WAS BORN

ADDRESS

CITY

STATE

+

# How to Use Your Complete Care Notebook



## WHAT IS A COMPLETE CARE NOTEBOOK?

---

Being the parent of a child with special health care needs can feel overwhelming at times. Your child may need care and services, on a regular basis, from many different types of providers. This *Complete Care Notebook* was designed to help you keep track of and organize important information about your child's health and healthcare.

## WHAT DOES THE COMPLETE CARE NOTEBOOK CONTAIN?

---

- » Forms for recording emergency medical information about your child.
- » Forms for recording your family's health history.
- » Forms for tracking your child's health.
- » A *Family Voices Resource Guide* that provides contact information on statewide agencies that assist families of children with special needs.
- » A glossary that defines healthcare terms and medical specialties.
- » A pocket folder to store important forms to take to medical visits.
- » A clear zipper pocket to save receipts, bills, business cards, etc.
- » A CD that you can use to print extra copies of *Complete Care Notebook* forms.



## HOW CAN THE COMPLETE CARE NOTEBOOK HELP ME?

---

In caring for your child with special health care needs, you may get information and paperwork from many sources. This *Notebook* will help you organize the most important information about caring for your child in a central place. The *Complete Care Notebook* makes it easier for you to find and share key information with others who are part of your child's care team.

Use your *Complete Care Notebook* to:

- » Store emergency information about your child and family.
- » File information about your child's health care history.
- » List telephone numbers for health care providers and community organizations.
- » Track changes in your child's medicines, treatments, and health conditions(s).
- » Keep track of medical appointments and conversations with healthcare providers.
- » Share new information about your child's care with doctors, school or daycare staff, and others caring for your child.
- » Track expenses related to your child's care.



## WHAT ARE SOME HELPFUL HINTS FOR USING MY CHILD'S COMPLETE CARE NOTEBOOK?

---

- » Store the *Complete Care Notebook* where it is easy to find.
- » Add new information to the *Complete Care Notebook* whenever there is a change in your child's diagnoses, treatment, and development.
- » Consider taking the *Complete Care Notebook* with you to appointments and hospital visits so that information you need will be close at hand.
- » Rather than carrying the entire *Notebook* to your child's appointments, you may choose to use the folder located in the back of the binder to carry individual pages of the *Notebook*.

## HOW DO I SET UP MY CHILD'S COMPLETE CARE NOTEBOOK?

---

1. Gather information you already have about your child's health.
  - » This may include reports from recent doctor's visits, a recent summary of a hospital stay, names and phone numbers of physicians, hospitals, and relatives, this year's school plan, test results, or informational pamphlets.
2. Decide which information about your child is most important to keep in the *Notebook* and file it in the appropriate section.
  - » Which of these sections could help you keep track of information about your child's health care?
  - » What information do you look up often?
  - » What information do others need for your child?
  - » How can you organize the *Complete Care Notebook* so it will be the most helpful to you?
3. Update the *Complete Care Notebook* regularly.
  - » Identify which forms require updating.
  - » Add information to the *Notebook* as it becomes available. For example, if you receive new information from health care providers, update the appropriate *Notebook* pages. Keep track of your child's condition(s) on a regular basis. Log phone conversations with providers, and track expenses related to your child's care.
  - » Extra copies of tracking forms can be printed from the CD found in the clear CD holder in the front of the *Notebook*.
  - » Store receipts, bills, business cards, etc in the clear zipper pocket.





+

# Emergency Information

*“Don’t find fault.  
Find a remedy.”  
Henry Ford*

This section provides forms with important information on your child’s health for medical providers in case of an emergency, including identification information, family contact information, and medical insurance.

This section is the most important part of the *Complete Care Notebook* to keep updated.

Below is a table describing the information you should record in each of the forms in this section.



+

Form	Use this form to record...
<b>CHILD’S EMERGENCY MEDICAL INFORMATION</b>	Important medical information needed for health providers in an emergency. Please note that this form should be updated often.
<b>FAMILY’S INFORMATION</b>	Contact information for your family, your child’s primary caregivers, and other emergency contacts.
<b>MEDICAL INSURANCE</b>	Medical insurance and policy information needed for emergency care providers.

+

+

+

+

## Emergency Information

CHILD'S DATE OF BIRTH

CHILD'S FIRST NAME

MIDDLE

LAST

NICKNAME

SOCIAL SECURITY #

ADDRESS

CITY

STATE

ZIP CODE

PHONE (       )

CELL PHONE (       )

BLOOD TYPE

CHILD'S CONDITION(S)

ALLERGIES

HOSPITAL REGISTERED FREQUENT FLYER

☐ YES

☐ NO

IF YES, NAME OF HOSPITAL

ETHNICITY

RELIGION

CUSTOMS THAT MAY AFFECT MEDICAL TREATMENT OR HEALTH CARE

PREFERRED LANGUAGE (WAY OF COMMUNICATING, SIGN, USE OF EQUIPMENT, TTY, COMMUNICATION BOARD, ETC.)

## Technology Dependence

SPECIAL TECHNOLOGY NEEDS (TUBES, CATHETERS, PORTS, ETC.)

PRECAUTIONS TO TAKE WHILE DEALING WITH TECHNOLOGY

☐ **DO NOT RESUSCITATE**

PARENT/GUARDIAN SIGNATURE

DATE

☐ **DO RESUSCITATE**

PARENT/GUARDIAN SIGNATURE

DATE

## Primary Care Provider

NAME

ADDRESS

CITY

STATE

ZIP CODE

PHONE NUMBER

PREFERRED HOSPITAL

## Current Medications

MEDICATION

DATE STARTED

DOSAGE

INSTRUCTIONS (INCLUDE TIME GIVEN)

## Last Medical Emergency

DATE

REASON

NAME OF HOSPITAL

ADDRESS

CITY

STATE

ZIP CODE

PHONE ( )

## Emergency Contacts

NAME

RELATIONSHIP

PHONE ( )

CELL PHONE ( )

NAME

RELATIONSHIP

PHONE ( )

CELL PHONE ( )

NAME

RELATIONSHIP

PHONE ( )

CELL PHONE ( )

## Family's Information

### MOTHER'S NAME

SOCIAL SECURITY #

ADDRESS

CITY

STATE

ZIP CODE

HOME ( )

WORK ( )

CELL ( )

FAX ( )

E-MAIL

### FATHER'S NAME

SOCIAL SECURITY #

ADDRESS

CITY

STATE

ZIP CODE

HOME ( )

WORK ( )

CELL ( )

FAX ( )

E-MAIL

### PRIMARY CAREGIVER, IF DIFFERENT FROM ABOVE (FOR EXAMPLE; GRANDPARENT, AUNT, OTHER LEGAL GUARDIAN)

NAME

SOCIAL SECURITY #

ADDRESS

CITY

STATE

ZIP CODE

HOME ( )

WORK ( )

CELL ( )

FAX ( )

E-MAIL

### OTHERS TO BE CALLED IN CASE OF AN EMERGENCY (CLERGY, OTHER RELATIVES AND FRIENDS)

NAME

SOCIAL SECURITY #

ADDRESS

CITY

STATE

ZIP CODE

HOME ( )

WORK ( )

CELL ( )

FAX ( )

E-MAIL

NAME

SOCIAL SECURITY #

ADDRESS

CITY

STATE

ZIP CODE

HOME ( )

WORK ( )

CELL ( )

FAX ( )

E-MAIL

## Primary Insurance

INSURANCE COMPANY

INSURANCE NUMBER

GROUP #

DEDUCTIBLE

POLICY HOLDER

EMPLOYER'S NAME

EMPLOYER'S ADDRESS

CITY

STATE

ZIP CODE

PHONE (       )

FAX (       )

## Secondary Insurance

INSURANCE COMPANY

INSURANCE NUMBER

GROUP #

DEDUCTIBLE

POLICY HOLDER

EMPLOYER'S NAME

EMPLOYER'S ADDRESS

CITY

STATE

ZIP CODE

PHONE (       )

FAX (       )

## Other Insurance or Health Plan

INSURANCE COMPANY

INSURANCE NUMBER

GROUP #

DEDUCTIBLE

POLICY HOLDER

EMPLOYER'S NAME

EMPLOYER'S ADDRESS

CITY

STATE

ZIP CODE

PHONE (       )

FAX (       )

*“Being a parent is a noble job.  
Never underestimate the power you have  
to help create a better future not only for  
your children, but for everyone.”*

*Anonymous*

# Health History



This section provides forms to record your family’s medical history and track changes in your child’s medical diagnosis and development. It is important to update this section if your child’s diagnosis and/or eating habits change.

Below is a table describing the information you should record in each of the forms in this section.

Form	Use this form to record...
<b>MOTHER’S PREGNANCY HISTORY</b>	Medications taken, problems, illnesses that occurred during the mother’s pregnancy.
<b>CHILD’S BIRTH HISTORY</b>	Date, name of hospital, and health conditions present on the day of your child’s birth.
<b>FAMILY MEDICAL HISTORY</b>	Illnesses or health conditions of the child’s mother, father, siblings, or other relatives.
<b>CHILD’S DIAGNOSIS</b>	Your child’s diagnosis, the date diagnosed, and the doctor who made the diagnosis.
<b>CHILD’S FEEDING HISTORY</b>	Changes in the type of food your child eats or the way he or she eats.
<b>CHILD’S DEVELOPMENT HISTORY</b>	The date when your child develops important skills, such as smiling, walking, speaking, and playing.



+

+

+

## Mother's Pregnancy History

HOW MANY MONTHS PREGNANT WERE YOU WHEN YOU FIRST SAW A DOCTOR?

HOW MANY TIMES DID YOU SEE THE DOCTOR DURING YOUR PREGNANCY?

DOCTOR/OBSTETRICIAN

PRACTICE/CLINIC NAME

ADDRESS

TELEPHONE (       )

### DRUGS AND MEDICATIONS TAKEN BY MOTHER BEFORE AND DURING PREGNANCY:

BEFORE PREGNANCY

HOW LONG?

DURING PREGNANCY

HOW LONG?

### MOTHER'S ILLNESSES DURING PREGNANCY:

DID YOU HAVE ANY PROBLEMS WITH THIS PREGNANCY OR WITH OTHER PREGNANCIES IN THE PAST?

ARE THERE ANY OTHER COMMENTS ABOUT YOUR PREGNANCY THAT YOU THINK ARE IMPORTANT?

# Child's Birth History

CHILD'S NAME	DATE OF BIRTH
BIRTH WEIGHT	LENGTH
WAS BABY FULL TERM (9 MONTHS)? <input type="checkbox"/> YES <input type="checkbox"/> NO IF NO, HOW MANY WEEKS EARLY WAS THE BABY BORN	
LENGTH OF LABOR	
TYPE OF DELIVERY: <input type="checkbox"/> NORMAL <input type="checkbox"/> BREECH <input type="checkbox"/> PRECIPITATE <input type="checkbox"/> CAESAREAN	
CHILD'S CONDITION AT BIRTH	
CHILD'S PROBLEMS FOLLOWING BIRTH	
DID MOTHER HAVE PROBLEMS WITH OTHER PREGNANCIES?	

NAME OF HOSPITAL WHERE CHILD WAS BORN	
ADDRESS	
TELEPHONE ( )	
HOW MANY DAYS DID YOUR CHILD STAY IN THE HOSPITAL AFTER BIRTH?	TO
DATE	DATE

NAME OF CHILD'S PRIMARY DOCTOR IN THIS HOSPITAL	
SPECIALTY	TELEPHONE ( )
ADDRESS	
CHILD'S APGAR SCORES: 1 MINUTE	5 MINUTES

NAME OF HOSPITAL CHILD WAS TRANSFERRED TO	
ADDRESS	TELEPHONE ( )
REASON FOR TRANSFER	
CHILD WAS IN THIS HOSPITAL FROM	TO
DATE	DATE

NAME OF CHILD'S PRIMARY DOCTOR IN THIS HOSPITAL	
SPECIALTY	TELEPHONE ( )
ADDRESS	

# Family Medical History

## MOTHER'S FAMILY (INCLUDE MOTHER'S PARENTS, BROTHERS, AND SISTERS)

HEALTH CONDITION(S)/ ILLNESSES	DATES DIAGNOSED	RELATIONSHIP TO CHILD

## FATHER'S FAMILY (INCLUDE FATHER'S PARENTS, BROTHERS, AND SISTERS)

HEALTH CONDITION(S)/ ILLNESSES	DATES DIAGNOSED	RELATIONSHIP TO CHILD

## CHILD'S SISTERS OR BROTHERS

HEALTH CONDITION(S)/ ILLNESSES	DATES DIAGNOSED	RELATIONSHIP TO CHILD

TIP: FAMILY MEDICAL HISTORY FORMS MAY CONTAIN REFERENCES TO "MATERNAL" OR "PATERNAL" RELATIVES.

"MATERNAL" MEANS ON THE MOTHER'S SIDE OF THE FAMILY; "PATERNAL" MEANS ON THE FATHER'S SIDE OF THE FAMILY.

# Child's Diagnosis

DIAGNOSIS

ABBREVIATION

ALSO CALLED

DOCTOR(S) WHO DIAGNOSED

SPECIALTY OF DOCTOR(S)

DATE(S) DIAGNOSED

DIAGNOSIS

ABBREVIATION

ALSO CALLED

DOCTOR(S) WHO DIAGNOSED

SPECIALTY OF DOCTOR(S)

DATE(S) DIAGNOSED

DIAGNOSIS

ABBREVIATION

ALSO CALLED

DOCTOR(S) WHO DIAGNOSED

SPECIALTY OF DOCTOR(S)

DATE(S) DIAGNOSED

DIAGNOSIS

ABBREVIATION

ALSO CALLED

DOCTOR(S) WHO DIAGNOSED

SPECIALTY OF DOCTOR(S)

DATE(S) DIAGNOSED

DIAGNOSIS

ABBREVIATION

ALSO CALLED

DOCTOR(S) WHO DIAGNOSED

SPECIALTY OF DOCTOR(S)

DATE(S) DIAGNOSED

DIAGNOSIS

ABBREVIATION

ALSO CALLED

DOCTOR(S) WHO DIAGNOSED

SPECIALTY OF DOCTOR(S)

DATE(S) DIAGNOSED

DIAGNOSIS

ABBREVIATION

ALSO CALLED

DOCTOR(S) WHO DIAGNOSED

SPECIALTY OF DOCTOR(S)

DATE(S) DIAGNOSED

DIAGNOSIS

ABBREVIATION

ALSO CALLED

DOCTOR(S) WHO DIAGNOSED

SPECIALTY OF DOCTOR(S)

DATE(S) DIAGNOSED

## Child's Feeding History

Sometimes children must have changes made to their diets. These changes may be either the type of food they eat or the way they eat it. Keeping track of these changes is important. If your child should ever have a problem with feeding, your doctor will want to know about your child's feeding history.

### WHEN YOUR BABY CAME HOME FROM THE HOSPITAL, WHAT TYPE OF FOOD DID HE/SHE EAT?

☐ BREAST MILK

☐ REGULAR FORMULA (SPECIFY WHAT BRAND, COLOR OF CAN)

☐ SPECIAL FORMULA (SPECIFY WHAT BRAND, COLOR OF CAN)

☐ HOMEMADE (LIST INGREDIENTS)

### IF YOUR BABY'S FEEDING HABITS CHANGED, WHAT WAS THE CHANGE AND WHY?

☐ BREAST TO BOTTLE

CHILD'S AGE

WHY?

☐ FORMULA CHANGE

CHILD'S AGE

WHAT WAS THE CHANGE?

WHY?

☐ BOTTLE TO CUP

CHILD'S AGE

WHY?

☐ STARTED SOLID FOOD

CHILD'S AGE

WHY?

☐ OTHER CHANGES (FOR EXAMPLE; TUBE FEEDING)

CHANGE

CHILD'S AGE

WHY?

CHANGE

CHILD'S AGE

WHY?

CHANGE

CHILD'S AGE

WHY?

CHANGE

CHILD'S AGE

WHY?

FEEDING HISTORY
FAVORITE FOODS
FOODS YOUR CHILD REFUSES TO EAT
FOOD ALLERGIES
HOW MUCH DOES HE/SHE EAT?
HOW LONG DOES IT TAKE YOUR CHILD TO TAKE A BOTTLE OR EAT A MEAL?
DOES YOUR CHILD HAVE ANY PROBLEMS WITH FOOD, SUCH AS SPITTING UP, VOMITING, DIARRHEA, REFUSING TO EAT, ETC.?
IS FEEDING DIFFICULT DURING MEALTIME?
TIP: THREE OR FOUR TIMES A YEAR YOU MAY WANT TO RECORD IN THIS BOOK, THE FOODS YOUR CHILD LIKES AND DISLIKES
SO YOU CAN HAVE A RECORD OF ANY CHANGE IN FOOD PREFERENCES.

+

+

+

## Child's Development History

The term “development” refers to an increase in skill and function, such as your child’s ability to move, talk, and take care of himself or herself. Because children with special health care needs may develop at a rate different from other children, it is important to keep a record of your child’s skill development.

### IMPORTANT SKILLS TO REMEMBER – LIST THE DATES YOUR CHILD:

FOLLOWED A MOVING TOY WITH EYES

HELD UP HEAD

REACHED FOR AN OBJECT

SMILED

ROLLED OVER

SAT WITHOUT SUPPORT

CRAWLED

IMITATED SOUNDS, SUCH AS “BYE-BYE”

PULLED UP TO A STANDING POSITION

WALKED WITHOUT SUPPORT

PICKED UP FOODS AND TRIED TO FEED SELF

SPOKE FIRST WORD

SPOKE SENTENCES

WALKED UP AND DOWN STAIRS

TOILET TRAINED

PLAYED WITH OTHERS AND SHARED TOYS

TIP: MANY DOCTORS AND NURSES PERFORM DEVELOPMENT SCREENINGS.

IF YOUR CHILD HAS A DEVELOPMENT SCREENING DONE, REQUEST A COPY AND FILE IT BEHIND THIS PAGE.





*“Expressing our confidence in our children is a powerful way to teach them to be confident in themselves.”*

*Anonymous*

# Care Team Contact List

Think of this section as an address book. This section provides forms to keep contact information for your child’s entire care team, including your child’s primary care provider, specialists, pharmacists, and childcare providers.

Below is a table describing the information you should record in each of the forms in this section.



Form	Use this form to record...
<b>PRIMARY CARE PHYSICIAN AND SPECIALISTS</b>	Contact information for your child’s primary care provider and any specialists your child sees, such as: <ul style="list-style-type: none"><li>» mental health care providers</li><li>» occupational, physical, or speech therapists</li><li>» case managers and other service coordinators.</li></ul>
<b>PHARMACIES / MEDICAL SUPPLIERS</b>	Contact information for the pharmacies where you get your child’s medication and supplies.
<b>HOME CARE PROVIDERS</b>	Contact information for any home nursing care providers for your child.
<b>RESPIRE CARE PROVIDERS</b>	Contact information for those who provide respite care when you or another care taker needs a break.
<b>CHILD CARE PROVIDERS</b>	Contact information for child care providers.
<b>COMMUNITY RESOURCES AND REFERRALS</b>	Contact and referral information for community resources (such as transportation services to get your child to appointments) and agencies to which your child is referred by a provider (such as WIC).

+

+

+

+

## Primary Care Physician

NAME

ADDRESS/CLINIC

CITY

STATE

ZIP CODE

PHONE (     )

FAX (     )

## Specialist 1

NAME

SPECIALTY

CLINIC/HOSPITAL/AGENCY

ADDRESS

CITY

STATE

ZIP CODE

PHONE (     )

FAX (     )

DATES CARE BEGAN AND ENDED

OTHER INFORMATION

## Specialist 2

NAME

SPECIALTY

CLINIC/HOSPITAL/AGENCY

ADDRESS

CITY

STATE

ZIP CODE

PHONE (     )

FAX (     )

DATES CARE BEGAN AND ENDED

OTHER INFORMATION

## Specialist 3

NAME

SPECIALTY

CLINIC/HOSPITAL/AGENCY

ADDRESS

CITY

STATE

ZIP CODE

PHONE (     )

FAX (     )

DATES CARE BEGAN AND ENDED

OTHER INFORMATION

+

+

## Pharmacy 1

NAME

ADDRESS

CITY

STATE

ZIP CODE

PHONE (     )

FAX (     )

HOURS

OTHER INFORMATION

## Pharmacy 2

NAME

ADDRESS

CITY

STATE

ZIP CODE

PHONE (     )

FAX (     )

HOURS

OTHER INFORMATION

## Medical Supplier 1

NAME

ADDRESS

CITY

STATE

ZIP CODE

PHONE (     )

FAX (     )

HOURS

OTHER INFORMATION

## Medical Supplier 2

NAME

ADDRESS

CITY

STATE

ZIP CODE

PHONE (     )

FAX (     )

HOURS

OTHER INFORMATION

## Home Care Provider 1

CONTACT PERSON

AGENCY

ADDRESS

CITY

STATE

ZIP CODE

PHONE (     )

FAX (     )

START DATE

OTHER INFORMATION

## Home Care Provider 2

CONTACT PERSON

AGENCY

ADDRESS

CITY

STATE

ZIP CODE

PHONE (     )

FAX (     )

START DATE

OTHER INFORMATION

## Home Care Provider 3

CONTACT PERSON

AGENCY

ADDRESS

CITY

STATE

ZIP CODE

PHONE (     )

FAX (     )

START DATE

OTHER INFORMATION

## Home Care Provider 4

CONTACT PERSON

AGENCY

ADDRESS

CITY

STATE

ZIP CODE

PHONE (     )

FAX (     )

START DATE

OTHER INFORMATION

## Respite Care Provider 1

CONTACT PERSON

AGENCY

ADDRESS

CITY

STATE

ZIP CODE

PHONE (     )

FAX (     )

START DATE

OTHER INFORMATION

## Respite Care Provider 2

CONTACT PERSON

AGENCY

ADDRESS

CITY

STATE

ZIP CODE

PHONE (     )

FAX (     )

START DATE

OTHER INFORMATION

## Respite Care Provider 3

CONTACT PERSON

AGENCY

ADDRESS

CITY

STATE

ZIP CODE

PHONE (     )

FAX (     )

START DATE

OTHER INFORMATION

## Respite Care Provider 4

CONTACT PERSON

AGENCY

ADDRESS

CITY

STATE

ZIP CODE

PHONE (     )

FAX (     )

START DATE

OTHER INFORMATION

## Child Care Provider 1

CONTACT PERSON

AGENCY

ADDRESS

CITY

STATE

ZIP CODE

PHONE (     )

FAX (     )

START DATE

OTHER INFORMATION

## Child Care Provider 2

CONTACT PERSON

AGENCY

ADDRESS

CITY

STATE

ZIP CODE

PHONE (     )

FAX (     )

START DATE

OTHER INFORMATION

## Child Care Provider 3

CONTACT PERSON

AGENCY

ADDRESS

CITY

STATE

ZIP CODE

PHONE (     )

FAX (     )

START DATE

OTHER INFORMATION

## Child Care Provider 4

CONTACT PERSON

AGENCY

ADDRESS

CITY

STATE

ZIP CODE

PHONE (     )

FAX (     )

START DATE

OTHER INFORMATION



## Service 1

CONTACT PERSON

AGENCY

SERVICE PROVIDED

REFERRED BY

ADDRESS

CITY

STATE

ZIP CODE

PHONE (     )

FAX (     )

OTHER INFORMATION

## Service 2

CONTACT PERSON

AGENCY

SERVICE PROVIDED

REFERRED BY

ADDRESS

CITY

STATE

ZIP CODE

PHONE (     )

FAX (     )

OTHER INFORMATION

## Service 3

CONTACT PERSON

AGENCY

SERVICE PROVIDED

REFERRED BY

ADDRESS

CITY

STATE

ZIP CODE

PHONE (     )

FAX (     )

OTHER INFORMATION

## Service 4

CONTACT PERSON

AGENCY

SERVICE PROVIDED

REFERRED BY

ADDRESS

CITY

STATE

ZIP CODE

PHONE (     )

FAX (     )

OTHER INFORMATION

# + Health Tracking

This section provides tips and advice about visits to the doctor and forms to use to keep track of doctor visits, test results, medications, treatments, and other information about your child's health care and development. You should also add to this section any notes you get from people providing treatment and services to your child.

On the next page is a table describing the information you should record in each of the forms in this section. Following the table you will find advice on the following topics:

- » General Tips For Medical Appointments
- » Information To Take To Each Appointment
- » Going to the Dentist
- » Information To Get At Each Appointment
- » What To Do If Your Child Is Hospitalized
- » Sample Release of Information Letter

*“If we take the time to truly see our children, to listen to what they say, watch what they do, find out how they’re feeling, it will be much easier for us to appreciate their struggles and successes as they learn to work toward a goal.”*

*Anonymous*



Form	Use this form to record...
<b>PHONE CONVERSATIONS &amp; VISITS WITH DOCTORS</b>	The date and results of phone calls and visits with your child's doctor(s).
<b>TEST RESULTS</b>	The date, reason, results, and recommended follow up for your child's hearing and vision tests, lab work, CT scans, MRIs, X-Rays, and other tests.
<b>HOSPITALIZATIONS AND SURGERIES</b>	The date of any hospitalization, name and location of the hospital, reason for admission, the attending physician, and the discharge date.
<b>HOSPITAL DISCHARGE PLANNING</b>	Any discharge instructions you receive, including information about special care, equipment, and medication.
<b>MEDICATIONS</b>	The name, start/stop dates, dosage, purpose of medication, who prescribed it, and side effects of taking the medication.
<b>TREATMENTS</b>	The date, type, and place where treatment is received, who prescribed it, and follow-up instructions. Examples of treatments include chemotherapy, dialysis, physical therapy, and occupational therapy.
<b>SEIZURE ACTIVITY FORM</b>	The date, time, and seizure-related activity if your child has a seizure.
<b>MEDICAL EQUIPMENT AND SUPPLIES</b>	The type of medical equipment or supplies your child uses, including where you got it, who prescribed it, why, and what your child's response was.
<b>ALLERGY RECORD</b>	Any allergic reactions your child has had, along with medications and instructions you received.
<b>DENTAL CARE RECORD</b>	Dental care your child has received.
<b>GROWTH TRACKING FORM</b>	Your child's age, height, weight, and head circumference.
<b>DAILY DIET TRACKING FORM</b>	Your child's meals and feeding information.
<b>CALENDAR</b>	Dates, times, and locations of appointments.

# Health Tracking Advice

## GENERAL TIPS FOR MEDICAL APPOINTMENTS

---

- » Take your child's medical records (diagnostic and surgical reports) when you see new physicians or other healthcare providers.
- » If your child is seen by more than one specialist, be sure that they are each aware of the others' involvement and that they share reports.
- » There may be more than one medical treatment option for your child's condition. Ask what can be expected from each of the possible options. Then decide which treatment you think will be best for your child.
- » If you are uncomfortable about your child's diagnosis or treatment, get a second opinion.
- » If you are not able to understand the medical language used by the doctor, specialist, or other professional, ask him/her to explain it.

## INFORMATION TO TAKE TO EACH APPOINTMENT

---

Before each appointment, prepare information for the doctor regarding your child's health, including:

- » An update of your child's health condition.
- » A description of any new symptoms, and when they began to develop.
- » A description of any improvements or setbacks for ongoing symptoms.
- » A list of any medications being used and any positive or negative effects that you have noted.
- » A list of any questions that you want to ask.

## GOING TO THE DENTIST

---

Before your child is examined, the dentist should have information regarding your child's medical condition and current care. Any precautions recommended by your child's medical specialist should be discussed with the dentist. It is also essential that you provide the dentist with a list of your child's current medications.

## INFORMATION TO GET AT EACH APPOINTMENT

---

Before completing the appointment with a health care provider, be sure that you have all the information you need, including:

- » A clear understanding of the diagnosis and plan for treatment.
- » Instructions for follow-up care (if needed).
- » Lab tests (when, where, and how you will get the results).
- » Medication (type, purpose, dosage, dispensing times, duration, and side effects).
- » Treatment/therapy (type, purpose, location, date, and time).
- » Available support services (agency/organization, address, and telephone).
- » Schedule for referral/follow-up appointment (physician, date, and time).
- » How to reach the physician with questions before the next appointment (name, email, or telephone).

## WHAT TO DO IF YOUR CHILD IS HOSPITALIZED

---

- » Bring your *Complete Care Notebook*.
- » Be sure that your insurance company, HMO, or any third party payer has been notified and complete pre-certification, if necessary.
- » Find out what services the hospital offers to families.
- » Children, especially younger ones, may be unusually clingy or fearful during or following hospitalization. Anticipate this and recognize it as the child's normal emotional response to separation from his or her family.
- » Prepare your child for the experience. Tell your child whether you will be able to stay with him or her overnight, how often you will visit, what his or her room will be like, and what kind of tests or treatment he or she will have. Your child may not be able to absorb all this information at once, so give it in small amounts. Repeat it as often as seems necessary over the course of several days and be ready to answer questions. Many hospitals have orientation programs for children.
- » When possible, stay with your child at the hospital. If you cannot stay with your child in the hospital, visit regularly and as often as possible.
- » At the end of a visit, make your child aware that you are leaving.
- » Before your child's discharge, ask for written instructions from your child's hospital care staff. Write the instructions on the Hospital Discharge Planning form in your *Complete Care Notebook*. Have the hospital care staff watch you performing any special care that will need to be continued when your child returns home, to be sure that you are doing it correctly.

# Sample Release of Information Letter

There may be times you wish to get a copy of your child's medical records. Requests for copies of medical records must be put into writing and given to the doctor, hospital, or clinic that has the records.

Below is a Sample Release of Information Letter. This sample letter shows the information that needs to be included in your request. Please note that some healthcare providers may require different information to release your child's records. Make sure to check with the physician or medical facility before sending your request.

June 28, 2004

Dear Dr. Jones:

I, Mary Doe, the parent/legal guardian of Christopher Doe, whose birth date is September 4, 2003, am requesting copies of medical records from Dr. Jones of the Family Medical Center by August 2004.

Please mail this information to the following address:

Mary Doe  
165 Oak Street, Apt 2  
Providence, RI 01234

Signed,

---

Parent/Legal Guardian

Date

+

+

+



## Phone Conversations and Visits with Doctors

DATE	PROVIDER NAME & PHONE NUMBER	ISSUES DISCUSSED / REASON SEEN / CARE PROVIDED	FOLLOW-UP



## 5. HEALTH TRACKING

+



## Hospitalizations and Surgeries

DATE	NAME AND ADDRESS OF HOSPITAL	ATTENDING PHYSICIAN	REASON FOR ADMISSION OR SURGERY	DISCHARGE DATE

## Hospital Discharge Planning

DISCHARGE INFORMATION

DATE

DOCTOR

NURSE

SOCIAL WORKER

HOSPITAL NAME

HOSPITAL ADDRESS

CITY

STATE

ZIP CODE

PHONE (     )

FAX (     )

WHO WAS PRESENT

## Special Care or Instructions

## Equipment Needed

## Medication *(include dosage and time given)*



# Medications

NAME (GENERIC/COMMON)	DATE		DOSAGE/ FREQUENCY	PURPOSE/ REASON ORDERED	DOCTOR PRESCRIBED BY	SIDE EFFECTS
	START	STOP				

+

+

+

Treatments				
DATE	TYPE OF TREATMENT	PRESCRIBED BY	LOCATION	FOLLOW-UP

# Seizure Activity Form

DATE/TIME								
LENGTH OF SEIZURE								
HEAD								
TURNED SIDE TO SIDE								
TURNED LEFT/RIGHT								
STAYED AT MIDLINE								
EYES								
LEFT ROLLED RIGHT/LEFT								
LEFT ROLLED UP/CLOSED								
LEFT STARED								
RIGHT ROLLED RIGHT/LEFT								
RIGHT ROLLED UP/CLOSED								
RIGHT STARED								
BOTH QUIVERED								
MOUTH								
OPENED/CLOSED								
BIT UPPER/LOWER LIP								
SECRETED SALIVA								
BREATHING								
NORMAL								
HELD BREATH SOMETIMES								
LABORED								
CRIED/WHINED								
UNCONSCIOUS								
SKIN COLOR								
NORMAL								
PALE								
RED								
BLUE								
OXYGEN GIVEN								
UPPER LIMBS								
SHIVERED/TREMORS								
JERKED								
STIFFENED/RIGID								
LOWER LIMBS								
SHIVERED/TREMORS								
JERKED								
STIFFENED/RIGID								
HANDS								
OPENED/FISTED								
WITNESSED BY								

+

+

+

## Medical Equipment and Supplies

TYPE OF EQUIPMENT OR SUPPLIES	PRESCRIBED BY	REASON PRESCRIBED	RESPONSE	VENDOR	CONTACT PERSON & PHONE NUMBER



## Allergy Record

DATE	ALLERGY	CAUSE OF REACTION	TYPE OF REACTION	MEDICATIONS & INSTRUCTIONS



Dental Care Record			
DENTIST'S NAME	DATE OF VISIT	REASON FOR APPOINTMENT	NOTES

+

+

+

## +

+

Daily Diet Tracking Form					
DATE	BREAKFAST	LUNCH	DINNER	SNACKS	NOTES

+

+

+

+

+

+

Calendar						
MONTH				YEAR		
SUNDAY	MONDAY	TUESDAY	WEDNESDAY	THURSDAY	FRIDAY	SATURDAY



*“Nothing is a waste  
of time if you use  
the experience wisely.”  
Auguste Rodin*

# Daily Routine

Form	Use this form to record...
<b>HOME-BASED MEDICAL HEALTHCARE SCHEDULE</b>	The type of care that is provided to your child and the time it is provided.
<b>GETTING TO KNOW MY CHILD</b>	Information for your child’s care providers, including your child’s ability to perform daily activities, cope with stress, communicate with others, express emotions, and any additional information that is important to your child’s character.

This section provides a space for you to record in detail the type and timing of care your child receives, either by you or home-based care providers.

Above is a table describing the information you should record in each of the forms in this section.

+

+

+

## +

+

+



## Getting to Know My Child

### ACTIVITIES OF DAILY LIVING

Describe your child's abilities to feed him or herself, bathe, get dressed, use the bathroom, comb hair, brush teeth, etc., including any special routines your child has for these activities. Describe what your child can do by him or herself and any help or equipment your child uses for these activities.

### MOBILITY

Describe how your child gets around. Include what your child can do by him or herself and any help or equipment your child uses to get around. Describe any activity limits and any special routines your child has.

**COMMUNICATION**

Describe your child's ability to communicate and to understand others. Include sign language, words, gestures, or any equipment or help your child uses to communicate or understand others. Include any special words your family and child use to describe things.

**REST/SLEEP**

Describe your child's ability to get to sleep and sleep through the night. Describe your child's bedtime routine and any security or comfort objects your child uses.

**SOCIAL/PLAY**

Describe how your child shows affection, shares feelings, or plays with other children. What works best to get your child to get along or cooperate with others? Describe your child's favorite things to do. Include any special family activities or customs.

**COPING/STRESS TOLERANCE**

What things upset your child? Stressful events might include new people or situations, a hospital stay, or procedures such as having blood drawn. What does your child do when upset or when he or she has “had enough.” Describe your child’s way of asking for help and things to do or say to comfort your child.

+

**RESPIRATORY**

Describe your child’s respiratory (breathing) needs including care or treatments that your child needs and any special techniques or precautions you use when giving care. Include any special routines your child has for respiratory care.

+

+

**NOW AND LATER**

Record your child's words and thoughts about his or her life now as well as in the future.  
What does your child do well now? What does your child want to be when he or she grows up?

**OTHER INFORMATION**

Include here any additional information that is important about your child.

GETTING TO KNOW MY CHILD ADAPTED FROM THE CARE NOTEBOOK DEVELOPED BY CHILDREN'S HOSPITAL AND  
REGIONAL MEDICAL CENTER, SEATTLE, WA AND THE WASHINGTON STATE DEPT OF HEALTH, OFFICE OF CHILDREN WITH  
SPECIAL HEALTH CARE NEEDS, 1998.



+

# Education Plan

This section provides a form to record the contact information of the schools your child attends throughout his or her childhood. It also contains information about Early Intervention and Special Education services in Rhode Island.

*“There are two lasting  
gifts we give our children,  
one is roots,  
the other is wings.”  
Anonymous*

+



+

+

+



## Education Record

PROGRAM / SCHOOL	ADDRESS	CONTACT PERSON	TELEPHONE NUMBER	DATES	COMMENTS



# Early Intervention and Special Education

+

## WHAT IS EARLY INTERVENTION?

---

Early Intervention (EI) serves children with developmental delays and their families. The program is for children younger than 3 years old who have a delay in one or more areas of development.

## HOW ARE EARLY INTERVENTION AND SPECIAL EDUCATION SERVICES RELATED?

---

Up until age 3, your child will receive Early Intervention services if he or she is eligible. When your child is 28 months old, you will be asked by EI to sign a release allowing a Special Education services representative from your school district to contact you. Your EI service coordinator will schedule a Transition Planning Meeting with you and a school district representative. Some children leaving EI will not be eligible for Special Education or related services, but every family should be introduced to a Special Education services representative from their school district.

+

## WHAT IS SPECIAL EDUCATION IN RHODE ISLAND?

---

Special Education programs run in all Rhode Island school districts to provide specially designed instruction to meet the unique needs of a child with a disability. The Rhode Island Department of Education (RIDE) is the state agency responsible for providing these services, which are free for families.

## WHAT SERVICES ARE AVAILABLE?

---

The base of the Special Education program is the Individualized Education Program (IEP). The IEP determines what accommodations, assistive technology, and support from school personnel are required to assist the student with a disability.

Children with disabilities are offered support services, such as:

- » Transportation
- » Speech-language therapy
- » Audiology services
- » Psychological services
- » Physical and occupational therapy
- » Recreation
- » Rehabilitative counseling
- » Medical services

+

## WHAT ARE PARENTS' RESPONSIBILITIES?

---

It is important to attend your child's IEP meetings every year and to continue to inform your child's school about his or her specific needs.

## WHO IS ELIGIBLE FOR SPECIAL EDUCATION?

---

A child aged 3 to 21 who has been evaluated by a medical professional and has a disability, such as:

- » Autism
- » Blindness
- » Deafness
- » Emotional disturbance
- » Mental retardation
- » Orthopedic impairment
- » Specific learning disabilities
- » Speech or language impairment
- » Traumatic brain injury

Children aged 3 through 5 can qualify for preschool Special Education and related services when the child is experiencing developmental delay or a disability.

## WHO CAN I CONTACT FOR MORE INFORMATION?

---

Early Intervention

*Call the Family Health Information Line at  
1-800-942-7434 and ask for the number to the EI provider  
site closest to you.*

Your Local School District  
Special Education Coordinator

*Look in the blue pages of your phone book or see the Family  
Voices Resource Guide in Section 9 of this Notebook.*

Rhode Island Department of Education  
Office of Special Populations

(401) 222-4600 x2504

Rhode Island Parent Information Network

(401) 727-4144

Rhode Island Disability Law Center

(401) 831-3150

+

+

+

*“Obstacles don’t have to stop you. If you run into a wall, don’t turn around and give up. Figure out how to climb it, go through it, or work around it.”*  
*Michael Jordan*

# Expense Tracking

This section provides forms for you to track expenses related to the care of your child. These expenses may be deductible from your annual taxes, so be sure to keep copies of these forms.

Below is a table describing the information you should record in each of the forms in this section.



Form	Use this form to record...
<b>MEDICAL EXPENSE LOG</b>	Billing information related to your child’s medical expenses.
<b>TRAVEL EXPENSE LOG</b>	Places traveled to, miles traveled, and additional expenses while traveling for your child’s health.

+

+

+



## Medical Expense Log

DATE	DESCRIPTION OF SERVICE	PROVIDER AND LOCATION	DATE OF BILL	BILL SENT TO	ACTION	AMOUNT PAID	BALANCE DUE

\*ADAPTED FROM *PAYING THE BILLS* BY NEW ENGLAND SERVE. NOTE: THIS SHEET MAY BE USED FOR INCOME TAX FILING PURPOSES. KEEP COPIES OF RECEIPTS.

+

+

+

Travel Expense Log

DATE	TRAVEL FROM	TRAVEL TO	MILES	ADDITIONAL EXPENSES (MEALS, LODGING, ETC.)	REASON FOR TRAVEL

NOTE: THIS SHEET MAY BE USED FOR INCOME TAX FILING PURPOSES. PLEASE KEEP COPIES OF RECEIPTS.

+

Inserted into your child's *Complete Care Notebook* is a copy of the *Family Voices Resource Guide* that provides a full listing of Rhode Island health care services for families of children with special health care needs.

The best way to use this resource is to refer to the *Guide's* table of contents, which lists services by topic and in alphabetical order. Below the topic headings are the names of Rhode Island organizations that provide each specific service.

This guide is updated every year. If you would like an updated copy of the *Family Voices Resource Guide*, contact the Rhode Island Parent Information Network (RIPIN) at 1-800-464-3399.

# Family Voices Resource Guide









Resource Guide  
For Families  
Of Children with  
Special Needs

Rhode Island Edition  
2003-2004



Family Voices  
at the



# Who Are We?

## Family Voices

A national grassroots clearinghouse for information and education about ways to improve healthcare for children with disabilities and chronic conditions. The Family Voices network includes families, coordinators in each state and region, and the national staff. Members of the network serve on local, state, and national boards and task forces; as staff for state health agencies or parent organizations; and as advisors to private and public health systems and research projects. Their mission is to bring the family perspective into policy discussions and decisions.

For more information contact:

Family Voices at the Rhode Island Parent Information Network

175 Main Street

Pawtucket, RI 02860

Phone: 401-727-4144

TDD: 401-727-4151

Fax: 401-727-4040

*Cindy Montero*

*Intake/Outreach Coordinator*

*x141*

*montero@ripin.org*

*Dawn Wardyga*

*Program Director*

*x158*

*familyvoices@ripin.org*

## Disclaimer

The information in this directory was obtained using Internet and print materials that were available at the time this directory was being compiled. Wherever possible, phone numbers, mailing addresses, descriptions, contact names, websites and email addresses have been provided. Efforts have been made to ensure that the information is accurate and current at the time of printing. The inclusion of an entry does not constitute an endorsement of the services or products provided by the organization, agency, or individual.

To report changes, add information, make suggestions regarding the format or content, or request copies of this directory, please complete the feedback form provided at the end of this directory and fax (401-727-4040) or mail (Family Voices at RIPIN, 175 Main Street, Pawtucket, RI 02860) it back to us.

## Acknowledgements

Family Voices, at the Rhode Island Parent Information Network (RIPIN), would like to acknowledge those who have given their time and thoughtful comments/edits to the production of this Resource Guide for Families of Children with Special Needs.

We are grateful to acknowledge the commitment of Jennifer Bowdoin, a RIPIN Board member, who provided us with motivation to compile this information and developed the first draft of the guide. We are also grateful to Claire Rosenbaum of the Sherlock Center on Disabilities and Susan Vandal, Intake Coordinator for Family Voices, for their hours and hours of reading, editing, rereading, and reediting of this document to make it as current, comprehensive, and concise as possible as of the time of printing.

We also acknowledge the patience and sense of humor of Amy Heffernan, Communications Coordinator at RIPIN, for doing the tedious work of formatting and putting the finishing touches on this resource guide for families of children with special needs. Finally, we sincerely thank the Rhode Island Department of Health, Division of Family Health, for their ongoing support of our work of providing information, education, advocacy, and peer support for children with special needs and their families.

# Table of Contents

<b>Early Childhood Service Birth to Five Years of Age</b>	2
Early Intervention	2
Early Head Start	3
Head Start	3
Child Outreach Screening	4
Parents as Teachers (PAT)	5
Home Instruction Program for Preschool Youngsters (HIPPY)	5
Childcare Programs	5
Options for Working Parents	6
Even Start Family Literacy	6
Family Outreach Program	6
<b>Education</b>	7
Rhode Island Department of Education	7
Special Education Directors by District	7
Special Education Contacts at State Operated Schools	9
State Staff Assignments	9
The Autism Support Center	10
Vocational Education for Students with Disabilities	10
GED Administration	10
Rhode Island Association of Private Special Education Schools (RIAPSES, Inc)	11
<b>Transition to Adult Life</b>	13
Regional Transition Centers	13
Supported Employment	13
Developmental Disabilities	15
Developmental Disabilities Councils of Other States in the Region	16
University Affiliated Programs	17
Vocational Assessment and Placement	17
Transportation Resources	18
Assistive Technology and Technology Access	18
Other Education Resources	19
<b>Health</b>	20
Programs for Children with Special Health Care Needs	20
General Health Resources	24
Prescription Medication Information	25
Specific Genetic Disorders and Disabilities	27
Hospitals	34
<b>Mental/Behavioral Health</b>	36
Family Education, Advocacy and Support	40
<b>Housing</b>	43
RI Housing and Mortgage Finance Company	43
Housing Resources Commission	43
<b>Other Resources for Families</b>	44
Women, Infants, Children Program (WIC)	44
<b>Family Fun</b>	45
<b>Elected Government Officials</b>	46

# Early Childhood Services Birth to Five Years of Age

## Early Intervention

Early Intervention (EI) serves children ages birth to 36 months who are at risk or have a disability. Anyone can refer to EI.

### Part C Program

#### Rhode Island Department of Health

Division of Family Health

David Hamel, Coordinator

Susan Curley, Client Services Coordinator

Cannon Building, Room 302

3 Capitol Hill

Providence, RI 02908-5097

Phone: 401-222-4632

Fax: 401-222-1442

[www.health.state.ri.us](http://www.health.state.ri.us)

### Early Intervention Programs

When contacting any site, please ask for the Intake Coordinator of Early Intervention.

#### *Children's Friend and Service*

621 Dexter Street

Central Falls, RI 02863

Phone: 401-331-2900

#### *Hasbro Children's Hospital*

593 Eddy Street

Providence, RI 02903

Phone: 401-444-3201

#### *James L Maher Center*

24 Hillside Avenue

PO Box 4390

Middletown, RI 02842

Phone: 401-884-2660

#### *Family Resources Community Action*

245 Main Street

Woonsocket, RI 02895

Phone: 401-766-0900

#### *J. Arthur Trudeau Memorial Center*

250 Commonwealth Avenue

Warwick, RI 02886

Phone: 401-823-1731

or 800-374-1914 (toll free)

or

350 Kingstown Road

Narragansett, RI 02882

401-783-6853

#### *The Groden Center*

86 Mount Hope Avenue

Providence, RI 02906

Phone: 401-274-6310

#### *Family Service*

55 Hope Street

Providence, RI 02906

Phone: 401-331-1350

#### *Meeting Street*

667 Waterman Avenue

East Providence, RI 02914

Phone: 401-438-9500

### Early Intervention (EI) Parent Consultant Program

Parent consultants are trained and work through the Rhode Island Parent Information Network. They are placed at each EI site to ensure family-centered practices, hold play groups, coffee hours and provide workshops.

Lisa Schaffran, Early Intervention Program Director

Rhode Island Parent Information Network

175 Main Street

Pawtucket, RI 02860

Phone: 401-727-4144 x153 or 800-464-3399 x153 (toll free in RI only)

Fax: 401-727-4040

[www.ripin.org](http://www.ripin.org)

[schaffran@ripin.org](mailto:schaffran@ripin.org)

## Other Early Intervention Resources

### *Interagency Coordinating Council (ICC)*

Advises and provides assistance to the RI Department of Health on Early Intervention programs

Dawn Wardyga, ICC Chair

Phone: 401-727-4144 x158 or 800-464-3399 x158

Fax: 401-727-4040

### *Early Intervention Central Directory*

Provides basic information about the Early Intervention Program in RI, as well as information about various services available for young children and their families.

Phone: 401-727-4144 or 800-464-3399 (toll free in RI only)

Also available online at: [www.ripin.org/centraldirectory.pdf](http://www.ripin.org/centraldirectory.pdf)

## Early Head Start

Early Head Start is a national program that provides comprehensive developmental services for low-income, preschool children under 3 and social services for pregnant women. Early Head Start focuses on four cornerstones essential to quality programs: child development; family development; community building; and staff development. The purpose of Early Head Start is to: enhance children's physical, social, emotional, and cognitive development; enable parents to be better caregivers of and teachers to their children; and help parents meet their own goals, including that of economic dependence.

### **Children's Friend and Service**

153 Summer Street

Providence, RI 02903

401-729-9179

### **C.H.I.L.D., Inc.**

160 Draper Avenue

Warwick, RI 02886

401-737-0403

### **Tri-Town Community Action Program**

1126 Hartford Avenue

Johnston, RI 02919

401-351-2750

### **Self Help/East Bay Early Head Start**

16 Liberty Street

Warren, RI 02885

401-245-2833

### **New Visions for Newport County**

Joel Peckham Center

654 Green End Avenue

Middletown, RI

401-846-5454

### **Cranston Child Development Center**

848 Atwood Avenue

Cranston, RI 02902

401-943-5160

## Head Start

Head Start is a national program that provides comprehensive developmental services for low-income, preschool children ages 3 to 5 and social services for their families. Head Start offers specific services that focus on education, social-emotional development, physical and mental health and nutrition.

### **C.H.I.L.D., Inc.**

Director: Lynda Dickinson

Disabilities Coordinator: Michelle

Wolstenholme

Early Head Start Coordinator: Sonya

Murphy

160 Draper Avenue

Warwick, RI 02886

401-737-0403

### **Providence Head Start**

Director: Sister Barbara McMichael/

Mary Dean

Disabilities Coordinator: Debra Saul

20 Almy Street

Providence, RI 02909

401-272-1760

### **Woonsocket Head Start and Day Care**

Director: Karen Bouchard

Disabilities Coordinator: Lisa Caswell

2 Bourdon Boulevard

Woonsocket, RI 02895

401-769-1850

### **Self Help/East Bay Head Start**

Director: Mary Nugent

Disabilities Coordinator: Debbie Keith

Early Head Start Coordinator: Janet

Marquez

16 Liberty Street

Warren, RI 02885

401-245-2833

### **New Visions for Newport County**

Director: Cindy Larson

Disabilities Coordinator: Kathy Stack

Joel Peckham Center

654 Green End Avenue

Middletown, RI 401-846-5454

### **Children's Friend and Service**

Director: Rosemary Soave

153 Summer Street

Providence, RI 02903

401-729-9179

### **Tri-Town Community Action**

Director: Susan Connaughton

Disabilities Coordinator: Julie Bircher

Early Head Start Coordinator: Rhonda Ferrell

1126 Hartford Avenue

Johnston, RI 02919

401-351-2750

### **Cranston Child Development Center**

Head Start and Early Head Start

Director: Jeanne Rheaume

Disabilities Coordinator: Judith Soscia

Early Head Start: Toni Enright

848 Atwood Avenue

Cranston, RI 02902

401-943-5160

### **South County Community Action Program**

Director: Carol Hemingway

Disabilities Coordinator: Heidi Nordman

1080 Kingstown Road

PO Box 3738

Peace Dale, RI 02883

401-789-3016

## Child Outreach Screening

Child Outreach Screening is a developmental screening program available to all children ages 3 through 5 offered through each local educational agency. It provides families with information about their child's development and offers information about other resources available in the community. Children are screened in the areas of motor, language, cognition, behavior and socialization, speech, vision and hearing. If concerns emerge as a result of a screening a referral is made to the local school district for a more in-depth evaluation in order to determine eligibility for special education and related services. The Rhode Island Department of Education monitors the Child Outreach Screening program.

Rhode Island Department of Education

Phone: 401-222-4600

### Child Outreach Coordinators

#### *Barrington*

Stephen Marchetti  
283 County Road  
Barrington, RI 02806  
401-247-3145

#### *Bristol-Warren*

Gail Peloquin  
151 State Street  
Bristol, RI 02806  
401-254-5930

#### *Burrillville / Foster / Glocester / North Smithfield / Scituate*

Marilyn Lang  
23 A Theodore Foster Drive  
North Scituate, RI 02857  
401-647-7560

#### *Central Falls*

Patricia Madden  
Registration and Outreach Center  
325 Cowden Street  
Central Falls, RI 02863  
401-727-6177

#### *Chariho*

Lisa Neill  
455A Switch Road  
Wood River Junction, RI 02894  
401-364-1160

#### *Coventry*

Barbara Bridge  
1675 Flat River Road  
Coventry, RI 02816  
401-822-9410

#### *Cranston*

Leslie Doonan  
45 Sprague Avenue  
Cranston, RI 02910  
401-785-8006

#### *Cumberland*

Kathleen Gibney  
2602 Mendon Road  
Cumberland, RI 02864  
401-722-4434

#### *East Greenwich / New Shoreham / Exeter / West Greenwich /*

*Narragansett / South Kingstown*  
Julie Wellen  
646 Camp Avenue  
North Kingstown, RI 02852  
401-295-2888

#### *East Providence*

Aurora Duarte  
80 Burnside Avenue  
East Providence, RI 02915  
401-433-6216

#### *Jamestown*

Peggy Wark  
75 Melrose Avenue  
Jamestown, RI 02835  
401-423-7020

#### *Johnston*

Susan Jadosz  
10 Memorial Drive  
Johnston, RI 02919  
401-233-1900 x2439

#### *Lincoln*

Muriel DesJardin  
1624 Lonsdale Avenue  
Lincoln, RI 02865  
401-726-1292

#### *Middletown / Newport / Little Compton / Portsmouth / Tiverton / Narragansett / New Shoreham*

Ann Marie McAndrews  
1 Frank Coelho Drive  
Portsmouth, RI 02871  
401-683-3570

#### *North Providence*

Mary Wojeck  
401-233-1100 x123  
Centerdale School  
11 George Street  
North Providence, RI 02911

#### *Pawtucket*

Joan Moran Phillips  
Creamer Administration Building  
Park Place, P.O. Box 388  
Pawtucket, RI 02860  
401-729-6511

#### *Providence*

Elaine Mackio  
797 Westminster Street  
Providence, RI 02903  
401-456-9331

#### *Smithfield*

Colleen Payton  
49 Farnum Pike  
Esmond, RI 02917  
401-231-6608

#### *Warren*

Helen Albernaz  
151 State Street  
Bristol, RI 02806  
401-245-1999

#### *Warwick*

Alice Freeman  
101 Lake Shore Drive  
Warwick, RI 02889  
401-734-3245

#### *Westerly*

Evie Martin  
44 Park Avenue  
Westerly, RI 02891  
401-348-2713

#### *West Warwick*

Carole Ognì  
401-822-8432  
10 Harris Avenue  
West Warwick, RI 02893

#### *Woonsocket*

Marybeth Wilcox-Ziepniewski  
McFee Administration Building  
108 High Street  
Woonsocket, RI 02895  
401-767-4643

## Parents As Teachers (PAT)

The Rhode Island Parent Information Network (RIPIN) manages this statewide home visiting program. RIPIN firmly believes that parents are their child's first and best teacher. Through home visits to parents with children from birth to five years of age, families are offered: 1) information on their child's growth and development, 2) access to state and community based resources, 3) opportunities to meet other parents with children of a similar age and 4) annual developmental screenings for their child.

Gladys Tiede, Program Director  
Rhode Island Parent Information Network  
175 Main Street  
Pawtucket, RI 02860  
Phone: 401-727-4144 x154 or 800-464-3399 x154 (toll free in Rhode Island only)  
Fax: 401-727-4040  
tiede@ripin.org  
www.ripin.org

## Home Instruction Program for Preschool Youngsters (HIPPY)

The Home Instruction Program for Preschool Youngsters (HIPPY) is a statewide visiting program for parents of children from three to five years of age. Offered by the Rhode Island Parent Information Network, HIPPY supports the development of school readiness through cognitive skill building, information about the local school district, parent-networking opportunities, and by connecting families to community resources.

Mary Doyle, Program Director  
175 Main Street  
Pawtucket, RI 02860  
Phone: 401-729-6509

## Childcare Programs

### Comprehensive Child Care Services Network

Comprehensive Child Care Services is a program that provides comprehensive childcare services to children age 3 through entry into kindergarten and their families. Comprehensive Child Care Services include assessment and individualized planning regarding children's health, early childhood education, children's mental health, and support for children with disabilities, nutrition and family education and empowerment.

Rhode Island Department of Human Services  
600 New London Avenue  
Cranston, RI 02920  
Phone: 401-462-5300

### Program Sites

*Comprehensive Community Action Program*  
311 Doric Avenue  
Cranston, RI 02910  
Phone: 401-467-9610

*Children's Network - Meeting Street*  
667 Waterman Avenue  
East Providence, RI 02914  
Phone: 401-438-9500

*Bay Net - West Bay Community Action Program*  
218 Buttonwoods Avenue  
Warwick, RI 02886  
Phone: 401-732-4666 x101

*Child Care Connection*  
25 Blackstone Valley Place  
Lincoln, RI 02865  
Phone: 401-334-0100



## Options for Working Parents

Options for Working Parents helps parents looking for child care and employers looking to set up child care resources for employees. This organization has a statewide computerized file of licensed child care centers, family child care homes, family day care systems, nursery schools, summer camps and after school programs. Options refers parents to child care providers, based on the type of care needed, the location of the facility, and any special amenities needed for the child. There is no fee for this service.

Options for Working Parents  
30 Exchange Terrace  
Providence, RI 02903  
Phone: 401-272-7510 or 800-244-8700

## Even Start Family Literacy Program

The purpose of this program is to help families become full partners in their children's education. The four components of this program are designed to provide families with the skills and resources to ensure family self-sufficiency with community involvement and support. The four components of the program are: (1) high quality early childhood education for children birth to seven years old; (2) adult literacy including Adult Basic Education, General Education Development (GED), English as a Second Language (ESL), and job training (3) parenting education and (4) parent involvement. Areas Served: Central Falls, Dorcas Place (serves Providence), Newport, Pawtucket, Tri-town Community Action (serves Smithfield and Johnston), Woonsocket

Charlotte Diffendale  
Rhode Island Department of Education  
Rhode Island Even Start Coordinator  
255 Westminster Street  
Providence, RI 02903  
Phone: 401-222-4600 x1-2457

### Even Start Coordinators

*Newport*  
Nancy Ryan  
Phone: 401-845-8579

*Tri-Town Community Action  
(Johnston / Smithfield)*  
Erika Greene  
Phone: 401-351-2750

*Central Falls*  
Mario Papitto  
Phone: 401-727-7700

*Woonsocket*  
Nancy Giambusso  
Phone: 401-765-3678

*Pawtucket*  
Heather Harrison  
Phone: 401-729-6293

*Dorcas Place (Providence)*  
Ginny Perelson  
Phone: 401-273-8886

## Family Outreach Program

The Family Outreach Program supports families and their children during the early years of childhood development. This program offers home visits and follow-up services that are designed to meet a variety of family needs. Through the Family Outreach Program, families and children are linked to community agencies and resources. Pregnant women and families with infants and young children up to age 5 are eligible for services.

Family Outreach Program  
Rhode Island Department of Health  
3 Capitol Hill, Room 302  
Providence, RI 02908  
Phone: 401-222-5949  
Fax: 401-222-1442

# Education

## Rhode Island Department of Education

Commissioner: Peter McWalters  
255 Westminster Street  
Providence, RI 02903  
Phone: 401-222-4600 x1-2001  
TTD Relay RI:  
Fax: 401-222-6030  
ride0001@ride.net  
www.ride.net

## Rhode Island Department of Education, Office of Special Needs

The Rhode Island Department of Education's Office of Special Needs provides assistance and support to schools and parents in meeting the special education needs of children in RI, including specially designed options to assist students with disabilities to meet performance standards. The Office of Special Needs operates a Consumer Complaint program staffed by legal counsel to ensure programs comply with federal and state regulations. Age of children served by Special Education is 3 years to 21 years of age.

Director: Thomas DiPaola  
Department of Education  
255 Westminster Street  
Providence, RI 02903-3400  
Phone: 401-222-4600  
TTD Relay RI 800-745-5555  
Fax: 401-222-6030  
tdipaola@ride.net  
www.ride.net  
*IEP Hotline: 401-222-4600 x1-2504*

## Special Education Directors by District

### Barrington

Anne De Fanti, Director  
PO Box 95283 County Road  
Barrington, RI 02806  
Phone: 401-247-3145  
Fax: 401-245-5003  
0034@ride.ri.net

### Bristol/Warren

Leslie Neubauer, Director  
151 State Street  
Bristol, RI 02809  
Phone: 401-253-4000 x222  
Fax: 401-253-1740  
ride4388@ride.ri.net

### Burrillville

Julian MacDonnell, Director  
92 North Main Street  
Pascoag, RI 02859  
Phone: 401-568-1307  
Fax: 401-568-4111  
rid22415@ride.ri.net

### Central Falls

Arlene Garrison, Director  
21 Hedley Avenue  
Central Falls, RI 02863  
Phone: 401-727-7707  
Fax: 401-727-7722

### Chariho (Charlestown, Hopkinton, Richmond)

Marcia Tambellini, Director  
455 A Switch Road  
Wood River Junction, RI 02894  
Phone: 401-364-1100  
Fax 401-364-1166

### Coventry

Virginia Schutttert, Director  
222 MacArthur Boulevard  
Coventry, RI 02816  
Phone: 401-822-9400 or 401-822-9410  
Fax 401-822-9406  
rid00958@ride.ri.net

### Cranston

John Blackburn, Executive Director,  
Pupil Personnel  
845 Park Avenue  
Cranston, RI 02910  
Phone: 401-785-8138  
Fax: 401-785-1958  
jblackburn@mail.cps.k12.ri.us

### Cumberland

Denise Ahern, Director  
2606 Mendon Road  
Cumberland, RI 02864  
Phone 401-658-1600  
Fax: 401-658-4620

### East Greenwich

Helen O'Hara, Director  
111 Pierce Street  
East Greenwich, RI 02818  
Phone: 401-885-3300  
Fax: 401-886-3203  
ride9487@ride.ri.net

**East Providence**

Michael Rock, Director  
80 Burnside Avenue  
East Providence, RI 02915  
Phone: 401-433-6216  
Fax: 401-437-3830

**Exeter/West Greenwich**

Maureen Decrezenzo, Director  
930 Nooseneck Hill Road  
West Greenwich, RI 02817  
Phone: 401-397-7420  
Fax: 401-392-0109  
decreasm@shmail.ewg.k12.ri.us

**Jamestown**

Robert Wall, Jr., Director  
55 Lawn Avenue  
Jamestown, RI 02835  
Phone: 401-423-7010  
Fax: 401-423-7012

**Johnston**

Steven Pereira, Director  
10 Memorial Drive  
Johnston, RI 02919  
Phone: 401-233-1900 x2432  
Fax: 401-233-1907  
rid26993@ride.ri.net

**Lincoln**

William Anderson  
1624 Lonsdale Avenue  
Lincoln, RI 02865  
Phone: 401-726-1292  
Fax: 401-726-1813  
rid21755@ride.ri.net

**Narragansett**

Patricia Pezzullo, Director  
25 Fifth Avenue  
Narragansett, RI 02882  
Phone: 401-792-9426  
Fax: 401-792-9429  
rid03429@ride.ri.net

**Newport**

Linda Martin, Director  
437 Broadway  
Newport, RI 02840  
Phone: 401-847-2100  
Fax: 401-849-0170  
epinto@cityofnewport.com

**Newport County Regional (Little Compton, Middletown, Portsmouth, Tiverton)**

Donald DeCosta, Director  
1 Frank Coehlo Drive  
Portsmouth, RI 02871  
Phone: 401-683-3570  
Fax: 401-683-3372

**New Shoreham**

Marie Blackburn, Director  
PO Box 249  
Block Island, RI 02807  
Phone: 401-466-5600  
Fax: 401-466-5610

**North Kingstown**

Daniel McGregor, Director  
100 Fairway Drive  
North Kingstown, RI 02852  
Phone: 401-268-6451  
Fax: 401-268-6455  
ride2052@ride.ri.net

**North Providence**

Robert Asekoff, Director  
11 George Street  
North Providence, RI 02911  
Phone: 401-233-1110  
Fax: 401-233-1106  
ride5191@ride.ri.net

**North Smithfield/Smithfield**

Robert Fricklas, Director  
PO Box 72  
Slatersville, RI 02876  
Phone: 401-766-1868  
Fax: 401-765-  
8764rid23060@ride.ri.net

**Northwest Special Education Region (Foster, Glocester, Foster/Glocester, Scituate)**

John Magner, Director  
23A Theodore Foster Drive  
North Scituate, RI 02857  
Phone: 401-647-4106  
Fax: 401-647-4107  
jtmagner@hotmail.com

**Pawtucket**

Cathy Fusco, Director  
Creamer Administration Building  
Park Place  
Pawtucket, RI 02860  
Phone: 401-729-6382  
Fax: 401-727-1641

**Providence**

Kenneth Swanson, Director  
Robert Lynch, Assistant Director  
797 Westminster Street  
Providence, RI 02908  
Phone: 401-456-9331  
Fax: 401-453-  
8699rid01479@ride.ri.net

**Smithfield**

Michael Moriarty, Director  
49 Farnum Pike  
Esmond, RI 02917  
Phone: 401-231-6608  
Fax: 401-232-0870Email:  
rid25811@ride.ri.net

**South Kingstown**

Roseann Lilientha, Interim Director  
307 Curtis Corner  
Wakefield, RI 02879  
Phone: 401-792-9652  
Fax: 401-792-9604  
rid25991@ride.ri.net

**Warwick**

Steven Lowery, Director  
1849 Warwick Avenue  
Warwick, RI 02889  
Phone: 401-734-3000  
Fax: 401-734-3003

**Westerly**

Mark Hawk, Director  
44 Park Avenue  
Westerly, RI 02891  
Phone: 401-348-2711  
Fax: 401-348-2707  
hawkm@ride.ri.net

**West Warwick**

Jeannette Roelf-Rothwell  
10 Harris Avenue  
West Warwick, RI 02893  
Phone: 401-822-8432  
Fax: 401-822-8430

**Woonsocket**

Denise Bloom, Director  
McFee Administration Building  
108 High Street  
Woonsocket, RI 02895  
Phone: 401-767-4600  
Fax: 401-767-4640  
ride4626@ride.ri.net

## **Metropolitan Career and Technical Center**

Danielle DeGennaro-Labbe, Special  
Education Director  
Shepard Building  
80 Washington Street  
Providence, RI 02903  
Phone: 401-277-5046  
Fax: 401-277-5049

## **Special Education Contacts at State Operated Schools**

### **RI Department of Children, Youth, and Families**

Colleen Hedden, Project Director  
610 Mount Pleasant Avenue  
Providence, RI 02908  
Phone: 401-457-4871  
Fax: 401-457-4511

### **RI Department of Corrections**

Timothy Murphy, Education Unit  
Administrator  
PO Box 8312  
Cranston, RI 02920  
Phone: 401-464-2507  
Fax: 401-464-2509

### **RI School for the Deaf**

Dr. Reginald Redding  
1 Corliss Park  
Providence, RI 02908  
Phone: 401-222-3525  
Fax: 401-222-6998

### **RI Training School**

Robert Dumais, Director  
300 New London Avenue  
Cranston, RI 02920  
Phone: 401-464-2061  
Fax: 401-464-1464

### **Davies Career and Technical High School**

Vicki Phelps, Special Education  
Director  
Stephen G. Thornton, Principal  
Jenckes Hill Road  
Lincoln, RI 02865  
Phone: 401-728-1500  
Fax: 401-728-8910

### **Metropolitan Regional Career and Technical Center**

Dennis Littky, Director  
80 Washington Street, Room 436  
Providence, RI 02903  
Phone: 401-277-5046  
Fax: 401-277-5049

### **ProvidenceUrban Collaborative Accelerated Program (UCAP)**

Robert DeBlois, Director  
75 Carpenter Street  
Providence, RI 02903  
Phone: 401-272-0881  
Fax: 401-273-7141  
[www.ucap.org](http://www.ucap.org)

## **State Staff Assignments**

Each school district is assigned an Education Consultant from the Office of Special Needs as listed below. School district personnel, parents, and any other person needing assistance concerning the assigned school district may contact the Education Consultant assigned to that district for assistance.

General Information: 401-222-3505

District Consultant: dial 401-222-4600 and the following extension

### **Bristol/Warren/East Providence**

Cathy Schulbaum, 1-2316

### **Burrillville/Central Falls/ Woonsocket**

Susan Wood, 1-2309

### **Chariho**

Kim Carson, 1-2336

### **Coventry/Cranston/Foster/ Gloucester/Scituate/ACI/ Davies Career and Technical Center**

David Sienko, 1-2216

### **Exeter/Narragansett/New**

**Shoreham/ South**

**Kingstown/West Greenwich**

Amy Cohen, 1-2408

### **Jamestown/East Greenwich/ Warren/ CVS Highlander School/RI Training School/ACI**

Cathy Schulbaum, 1-2316

### **Johnston/Lincoln/Cumberland/ North Providence/ Pawtucket/ International Institute School**

Ina Woolman, 1-2318

### **Little Compton/Barrington/**

**Tiverton/Middletown/**

**Newport/Portsmouth**

Barbara Burgess, 1-2363

### **North Kingstown/Providence/ The Met School/RI School for the Deaf**

Sally Radford, 1-2315

### **North Smithfield/Smithfield**

Susan Wood, 1-2309

### **Warwick/Westerly/West Warwick/Kingston Hill School**

Kim Carson, 1-2336

## **The Autism Support Center**

Provides a comprehensive, coordinated system of services to meet the needs of individuals and their families with Autism Spectrum Disorders (ASD). Consulting teams are available to assist school personnel with workshop and in-service programs, consultations, classroom design and curriculum and programming issues. The project also offers an 8-week training series for parents and professionals working with children with ASD in the home.

Sue Constable  
Department of Education  
Office of Special Needs  
255 Westminister Street  
Providence, RI 02903  
Phone: 401-222-4600 x1-2014  
Fax: 401-222-6030  
rid23926@ride.ri.net

## **Vocational Education for Students with Disabilities, RI Transition Project for Youth with Disabilities, State Department of Education**

Shepard Building  
255 Westminister Street  
Providence, RI 02903-3400  
Phone: 401-222-4600 x1-2216

## **GED Administration**

Robert Mason  
Department of Elementary and Secondary Division  
Shepard Building  
255 Westminister St.  
Providence, RI 02903-3414  
Phone: 401-222-4600 x1-2180  
www.ridoe.net

## Rhode Island Association of Private Special Education Schools (RIAPSES, Inc)

RIAPSES is a group of specialized educational programs that work collaboratively with RI public schools. All of the programs are approved by the RI Department of Education. These programs exist to meet a variety of intensive needs for students and their families by providing full time placements, joint services, and consultation in a variety of settings. The following schools are part of RIAPSES.

### **St. Andrew's School**

John D. Martin, Headmaster  
Audrey Lacher-Katz, Director of  
Special Education  
63 Federal Road  
Barrington, RI 02806-2407  
401-246-1230

### **Cornerstone School**

Kenneth W. Andrew  
665 Dyer Avenue  
Cranston, RI 02920  
401-942-2388

### **NFI/ACE Program**

Mary Anne McIntyre, Director of  
Special Education  
735 New London Avenue  
Cranston, RI 02920  
401-946-2020

### **Valley Community School**

James L. DePasquale, Principal  
Alan N. Cafferty, Director of Special  
Education  
83 Rolfe Street  
Cranston, RI 02910  
401-941-9707

### **Emma Pendleton**

Dr. Kevin P. Myers, Director of Special  
Education  
Bradley Hospital  
1011 Veterans Memorial Parkway  
East Providence, RI 02915  
401-432-1130

### **Meeting Street School**

Pat Ferri, Director of Educational  
Programs/Director of Special  
Education  
667 Waterman Avenue  
East Providence, RI 02914  
401-438-9500

### **Camp E-Hun-Tee**

Dr. O. William Hilton, Jr., Director of  
Special Education  
One Camp E-Hun-Tee Place  
Exeter, RI 02822  
401-539-7775

### **Harmony Hill School, Inc.**

Terrence J. Leary  
Ann Marie Dubuque, Director of  
Special Education  
63 Harmony Hill Road  
Chepachet, RI 02814  
401-949-0690

### **The Spurwink School II**

Raymond A. Arsenault  
Carleen Bellaire, Director of Special  
Education  
365 River Road  
Lincoln, RI 02865  
401-334-2222

### **Valley Community School**

James L. DePasquale, Principal  
Kathleen G. Weber, Director of Special  
Education  
60 Hammarlund Way  
Middletown, RI 02842  
401-849-7452

### **Ocean Tides, Inc.**

Jane E. Genereux, Principal  
Marjorie J. Hanson, Director of Special  
Education  
635 Ocean Road  
Narragansett, RI 02882  
401-789-1016

### **James L. Maher School**

John H. Maher  
Barbara S. Schiaroli, Director of  
Special Education  
120 Hillside Avenue  
Newport, RI 02840  
401-846-3518

### **George N. Hunt Campus School**

Bernard J. Smith  
Cindy Turbitt, Director of Special  
Education  
St. Mary's Home for Children  
440 Fruit Hill Avenue  
North Providence, RI 02911  
401-353-3900 x311

### **Valley Community and Day School**

James L. DePasquale, Principal  
Cynthia Houston, Director of Special  
Education  
249 Roosevelt Avenue  
Pawtucket, RI 02860  
401-722-3513

### **Tides Learning Center**

Brother Michael Reis  
Michael J. Capalbo, Director of Special  
Education  
242 Dexter Street  
Pawtucket, RI 02860  
401-724-8060

### **The Bradley School**

Dr. Kevin P. Myers, Director of Special  
Education  
2836 East Main Road  
Portsmouth, RI 02871  
401-682-1816

### **Center for Individualized Training and Education**

Laurel M. Scorpio, Program  
Director/Director of Special  
Education  
15 Bough Street  
Providence, RI 02909  
401-351-0611

### **Metropolitan Career and Technical Center**

401-277-5046  
*Downtown Campus*  
Danielle DeGennaro-Labbe, Director  
of Special Education  
80 Washington Street  
Providence, RI 02903  
*Peace Street Campus*  
Danielle DeGennaro-Labbe, Director  
of Special Education  
362 Dexter Street  
Providence, RI 02907

### **Mount Pleasant Academy**

Joan L. Colwell, Director of Special  
Education  
1246 Chalkstone Avenue  
Providence, RI 02909  
401-521-4335

**North American Family Institute  
Alternatives Program**

Robert Dumais, Director of Special  
Education  
350 Duncan Drive  
Providence, RI 02906  
401-453-4740

**Ocean Tides School**

Marjorie J. Hanson, Director of Special  
Education  
260 Highland Avenue  
Providence, RI 02906  
401-861-3778

**Pathways Strategic Teaching  
Center of Kent County RIARC**

Margaret Deslaurier  
401-739-2700

**Rhode Island School for the Deaf**

Dr. Reginald Redding, Principal  
1 Corliss Park  
Providence, RI 02908  
401-222-3525

**School One**

Denise M. Jenkins  
Dr. Janice DeFrances, Director of  
Special Education  
220 University Avenue  
Providence, RI 02906-5434  
401-331-2497

**Tavares Pediatric Center**

Eugene F. Tavares, Administrator  
Danielle DeGennaro-Labbe, Director  
of Special Education  
101 Plain Street  
Providence, RI 02903  
401-272-7127

**The Groden Center, Inc.**

Dr. June Groden and Dr. Gerald Groden,  
Co-Directors  
William Anderson, Director of Special  
Education  
86 Mount Hope Avenue  
Providence, RI 02906  
401-274-6310

**The Providence Center School**

Martha Morris, Principal/Director of  
Special Education  
520 Hope Street  
Providence, RI 02906  
401-276-4000

**Tides Learning Center**

Brother Michael Reis  
Michael J. Capalbo, Director of Special  
Education  
790 Broad Street  
Providence, RI 02905  
401-467-8228

**Turning the Corner School  
Program**

Denise Bloom, Interim Director of  
Special Education  
58 Dartmouth Street  
Providence, RI 02907  
401-785-8446

**Vocational Resources, Inc.**

Paul Pickens  
Robert M. Sherman, Director of  
Special Education  
100 Houghton Street  
Providence, RI 02904  
401-861-2080

**South Shore School**

Kenneth Andrews, Acting Director of  
Special Education  
730 Kingstown Road  
Wakefield, RI 02879  
401-783-1150

**Eleanor Briggs School**

Barbara A. Dickerson, Director of  
Special Education  
116 Long Street  
Warwick, RI 02886  
401-732-1540

**Francis B. Sargent Rehabilitation  
Center**

Marilyn F. Serra  
800 Quaker Lane  
Warwick, RI 02818  
401-886-6600

**Trudeau Education Services**

Director of Special Education  
3445 Post Road  
Warwick, RI 02886

**Tides Learning Center**

Br. Michael Reis  
Michael J. Capalbo, Director of Special  
Education  
222 Washington Street  
West Warwick, RI 02893  
401-739-2700

**New Pride School/Hillside**

James D. Williams  
Denise Bloom, Interim Director of  
Special Education  
115 Ricard Street  
Woonsocket, RI 02895  
401-762-0769

**The ARC of Northern Rhode  
Island**

Gerald P. Ventre  
Mary Ellen Dubuc, Director of Special  
Education  
80 Fabien Street  
Woonsocket, RI 02895  
401-769-9720

**Viola M. Berard School**

James V. Gallagher, Director of Special  
Education  
181 Cumberland Street  
Woonsocket, RI 02895-0856  
401-766-3330 x7148



# Transition to Adult Life

For students with special needs who have an Individualized Education Plan (IEP) and who are age fourteen or older, planning for their life after high school must be part of their IEP. This is called Transition Planning. The transition planning process can be complex and involve many issues. A good overview of the transition planning process and related issues is the publication, Here's to Your Student's Future! A Parent's Guide to Transition Planning. You can receive a copy of this guidebook and other information for families on Transition Planning by calling: Rhode Island Parent Information Network at 401-727-4144 x125 or 800-464-3399 x125

## Regional Transition Centers

The RI Regional Transition Centers provide information, training and technical assistance to teachers, administrators and families of students in special education ages 14-21 who are preparing for the transition from school to adult life. The Centers offer a resource and curriculum library and coordinate regional training and information events through their Regional Transition Advisory Committees (TAC).

The Transition Centers also house the Regional Vocational Assessment Centers. These centers provide vocational assessment services for students in special education ages 14-21 who are eligible for the services of the Office of Rehabilitation Services (ORS). The Assessment Centers assist students with their personal career goals through career counseling, vocational testing and community based work experiences. Information from the assessment is shared with the IEP teams and used to set IEP goals for employment, post-secondary education and training, community participation and independent living. Referrals are made by IEP Teams or directly through the Office of Rehabilitation Services (ORS).

### East Bay

Coordinator: Carolyn Aspinwall  
317 Market Street  
Warren, RI 02885-2637  
Phone: 401-245-2045 x303  
Fax: 401-245-9332

### Northern Rhode Island

Coordinator: Jane Slade  
2352 Mendon Road  
Cumberland, RI 02864-3715  
Phone: 401-658-5790  
Fax: 401-658-4012

### Other Transition-Related Resource

Paul Sherlock Center on Disabilities  
Rhode Island College  
600 Mt. Pleasant Avenue  
Providence, RI 02908  
Phone: 401-456-8072  
[www.uapri.org](http://www.uapri.org)

### West Bay

Coordinator: Rosemary Lavigne  
144 Bignall Street  
Warwick, RI 02888-1005  
Phone: 401-941-8353 x16  
Fax: 401-941-8535

### Southern Rhode Island

Coordinator: Alice Woods  
PO Box 552  
Narragansett, RI 02882-0552  
Phone: 401-295-2888  
Fax: 401-295-3232

## Supported Employment (State Agencies which contract Supported Employment)

### RI Department of Human Services, Office of Rehabilitative Services (ORS)

40 Fountain Street  
Providence, RI 02903  
Phone: 401-421-7005  
TDD: 401-421-7016  
[www.ors.state.ri.us](http://www.ors.state.ri.us)

### RI Department of Mental Health, Retardation, and Hospitals

#### Division of Developmental Disabilities, Division of Integrated Mental Health Services

Barry Hall  
14 Harrington Road  
Cranston, RI 02920-3080  
Phone: 401-462-3291  
TDD: 401-462-6087  
[www.mhrh.state.ri.us](http://www.mhrh.state.ri.us)



**Vocational Resources, Inc.**

VRI's mission is to provide services that expand vocational and economic opportunities for people with disabilities and related challenges in order to enhance their capacity for independent living, increased quality of life, and work.

Vocational Resources, Inc.

100 Houghton Street

Providence, RI 02904

Phone: 401-861-2080

TTY: 401-331-2830

Fax: 401-454-0889

Satellite offices:

Kingston: 401-782-0022; 401-782-1346 (TTY)

Newport: 401-849-6888

**Parents and Friends for Alternate Living (PAL)**

Supports people with a disability and their families as they advocate for themselves. It promotes individual direction and supports through a variety of demonstration projects to provide respite and recreation opportunities to Rhode Islanders who have a disability and their family members.

Doreen McConaghy, Executive Director

Parents and Friends for Alternate Living

PO Box 8885

Cranston, RI 02920

Phone: 401-785-2100

Fax: 401-785-2186

Email: [PAL@IDS.net](mailto:PAL@IDS.net)

# **Developmental Disabilities**

## **The Division of Developmental Disabilities**

PO Box 20523  
Cranston, RI 02920  
Phone: 401-462-3234  
Social Service: 401-462-3234  
Quality Assurance: 401-462-2629  
TDD: 401-462-6087  
Fax: 401-462-6189  
[www.mhrh.state.ri.us](http://www.mhrh.state.ri.us)

## **Rhode Island ARC**

99 Bald Hill Road  
Cranston, RI 02920  
Phone: 401-463-9191

## **National Association of Developmental Disabilities Councils (NADDC)**

The NADDC provides support and assistance to member Councils. The NADDC promotes national policy that provides persons with developmental disabilities the opportunity to make choices about the quality of their lives and to be included in the community.

National Association of Developmental Disabilities Councils (NADDC)  
1234 Massachusetts Avenue, NW, Suite 103  
Washington, DC 20005  
Phone: 202-347-1234  
Fax: 202-347-4023  
[NADDC@igc.apc.org](mailto:NADDC@igc.apc.org)  
[www.igc.org/NADDC](http://www.igc.org/NADDC)

## **Rhode Island Developmental Disabilities Council**

The Rhode Island Developmental Disabilities Council was established in 1971 by a federal law that requires all states to have planning councils. The Council has 24 members who are appointed by the Governor. Most members are people with developmental disabilities or relatives or guardians of people with developmental disabilities. Other members represent state and private agencies that provide services to people with disabilities. The Council works to make Rhode Island a better place for people with developmental disabilities to live, work, go to school, and be part of the community. Council members come together to discuss issues, solve problems, and plan for better services. The Council also involves people in the community in its planning. The Council is dedicated to improving the independence, productivity, integration, and inclusion of people with developmental disabilities.

Marie Citrone, Executive Director  
400 Bald Hill Road Suite 515  
Warwick, RI 02886  
Voice/TDD: 401-737-1238  
Fax: 401-737-3395  
[riddc@riddc.org](mailto:riddc@riddc.org)  
[www.riddc.org](http://www.riddc.org)

## **Developmental Disabilities Councils of Other States in the Region**

### **Connecticut Developmental Disabilities Council**

460 Capitol Avenue  
Hartford, CT 06106-1308  
Phone: 860-418-6160  
TTY: 860-418-6172  
Fax: 860-418-6003  
[www.state.ct.us/ctcdd](http://www.state.ct.us/ctcdd)

### **Maine Developmental Disabilities Council**

Nash Building  
139 State House Station  
Augusta, ME 04333-0139  
Phone: 207-287-4213  
Fax: 207-287-8001

### **Massachusetts Developmental Disabilities Council**

174 Portland Street, 5th Floor  
Boston, MA 02114  
Phone: 617-727-6374 x108  
TTY: 617-727-1885  
[www.state.ma.us/mddc](http://www.state.ma.us/mddc)

### **New Hampshire Developmental Disabilities Council**

The Concord Center  
10 Ferry Street Unit 315  
Concord, NH 03301-5004  
Phone: 603-271-3236 or 800-735-2964 (toll free/TDD)  
Fax: 603-271-1156

### **Vermont Developmental Disabilities Council**

103 South Main Street  
Waterbury, VT 05671-0206  
Phone: 802-241-2612 or 888-317-2006 (toll free/TDD)  
[www.ahs.state.vt.us/vtddc](http://www.ahs.state.vt.us/vtddc)

## **University Affiliated Programs**

Authorized by Federal legislation to help states and local communities respond to the needs of people with developmental disabilities and their families, University Affiliated Programs (UAPs) serve as a liaison between the academic world and the developmental disabilities service delivery system. UAPs network with and provide assistance to state agencies, their local affiliates, and to various nongovernmental, consumer-based organizations.

### **American Association of University Affiliated Programs for Persons with Developmental Disabilities (AAUAP)**

8630 Fenton Street, Suite 410  
Silver Spring, MD 20910  
Phone: 301-588-8252  
Fax: 301-588-2842  
info@aauap.org  
www.aauap.org

### **Paul V. Sherlock Center on Disabilities**

Rhode Island College  
Institute for Developmental Disabilities  
600 Mount Pleasant Avenue  
Providence, RI 02908  
Phone: 401-456-8072  
Fax: 401-456-8150  
TTY: 401-456- 8773  
www.uapri.org

## **Vocational Assessment and Placement**

### **Groden Center**

86 Mount Hope Avenue  
Providence, RI  
Phone: 401-274-6310

### **Vocational Resources, Inc./Goodwill**

100 Houghton Street  
Providence, RI  
Phone: 401-861-2080

### **Vocational Rehabilitation Services**

Empowers individuals with disabilities to choose, prepare for, obtain and maintain employment; economic self-sufficiency, independence, and integration into society. Program Disability Determination Services.

Raymond A. Carroll, Administrator  
Department of Human Services, Office of Rehabilitation Services  
40 Fountain Street  
Providence, RI 02903  
Phone: 401-421-7005 x301  
rcarroll@ors.state.ri.us  
www.ors.state.ri.us

### **Wise Voices (State Run Group Homes)**

DDD @MHRH RI Community Living and Support  
c/o RICLAS  
Simpson Hall  
PO Box 20523  
Howard Avenue  
Cranston, RI 02920  
Phone: 401-462-2796

## Transportation Resources

### **RIDE - RIPTA Para Transit Service**

ADA Americans with Disabilities Act Transit Program Copies of RIPTA's current program for people with disabilities are available in large print, Braille or on audiotape by calling. Also offered is Flex Service, which is service for suburban and rural areas that have little or no fixed route service. You must call 48 hours in advance.

265 Melrose Street  
Providence, RI 02907  
Phone: 401-784-9500 x153  
TDD: 401-784-9524  
[www.ripta.com](http://www.ripta.com)

### **PARI Independent Living Center**

500 Prospect Street  
Pawtucket, RI 02860  
Voice/TDD: 401-725-1966  
Fax: 401-725-2104

### **OSCIL (Ocean State Center for Independent Living)**

59 West Shore Road  
Warwick, RI 02889  
Phone: 401-738-1013  
TDD: 401-738-1015  
Fax: 401-738-5118  
Hispanic Program: 401-738-5118  
Kingston Office: 401-782-9400  
[www.oscil.org](http://www.oscil.org)

## Assistive Technology and Technology Access

### **Tech ACCESS Center of Rhode Island**

A private, nonprofit resource center that serves people with disabilities who are interested in assistive technology. Assistive Technology is any device that helps a person with a disability function better at home, work, school, or in the community. Information and Referral Services regarding assistive technology products, funding, and services are provided at no charge. Tech ACCESS also provides referrals to service providers, vendors, protection and advocacy services, etc.

100 Jefferson Boulevard  
Warwick, RI 02888  
Voice/TYY: 800-916-8324  
Fax: 401-463-3433  
[techaccess@techaccess-ri.org](mailto:techaccess@techaccess-ri.org)  
[www.techaccess-ri.org](http://www.techaccess-ri.org)

### **Rhode Island Assistive Technology Access Partnership**

The intent of the partnership is to bring about systems change through a comprehensive, consumer-responsive partnership of RI resources to maximize the timely delivery of appropriate assistive technology devices and services to Rhode Islanders with disabilities of all ages. The partnership includes special emphasis on minorities, the poor, and limited-English speaking populations.

Rhode Island Assistive Technology Access Partnership  
Office of Rehabilitation Services  
40 Fountain Street  
Providence, RI 02903  
English: 401-421-7005 x310  
Spanish: 401-272-8090  
Cambodian: 401-272-7990  
TTY: 401-421-7016  
Fax: 401-421-9259  
[www.atap.state.ri.us](http://www.atap.state.ri.us)

## **Other Education Resources**

### **Rhode Island Parent Information Network**

175 Main Street  
Pawtucket, RI 02860  
Phone: 401-727-4144 or 800-464-3399 (toll free in Rhode Island only)  
Fax: 401-727-4040  
[www.ripin.org](http://www.ripin.org)

### **Parent Support Network**

400 Warwick Avenue  
Warwick, RI 02886  
Phone: 401-467-6855 or 800-483-8844 (toll free)

### **Parent Teacher Association (PTA)**

RIC Campus-Building #6  
600 Mt. Pleasant Avenue  
Providence, RI 02908  
Phone: 401-272-6405  
[ri\\_office@pta.org](mailto:ri_office@pta.org)

### **Special Education Resource and Service**

[www.specialeducation.org](http://www.specialeducation.org)

### **Rhode Island Parents' Paper**

[www.parenthoodweb.com](http://www.parenthoodweb.com)

### **Assistive Technology in Education**

[at-advocacy.phillynews.com/index.html](http://at-advocacy.phillynews.com/index.html)

## Health

The following is a listing of systems that encompass health related services and issues. Please remember that this is a guide and that all services may not be available to all families. Call the specific agency or group for detailed information.

### **Rhode Island Department of Health, Division of Family Health**

#### **Family Health Information Line**

The Family Health Information Line is a toll-free telephone service for anyone who needs information about programs and services to improve the health of families and their children. A bilingual information specialist can answer questions about the following programs and services: Women Infants and Children Program (WIC); immunizations; the Early Intervention Program; lead poisoning prevention; parenting; adolescent health; family planning; Medical Assistance; Food Stamps; etc. If the information specialist cannot answer the question(s), referrals are made to community agencies.

3 Capitol Hill, Room 302

Providence, RI 02908

800-942-7434

### **Programs for Children with Special Health Care Needs**

#### **Department of Health, Office for Families Raising Children with Special Health Care Needs**

Chief: Deborah Garneau

3 Capitol Hill

Providence, RI 02908

Phone: 401-222-5929

[www.health.state.ri.us](http://www.health.state.ri.us)

#### **Rhode Island Medical Assistance Program**

This federal and state funded program, also known as Medicaid, pays for health care services for eligible children and families, individuals with disabilities and the elderly. The Department of Human Services administers the RI Medical Assistance Program.

Rhode Island Department of Human Services, Center for Child and Family Health

600 New London Avenue

Cranston, RI 02920

English: 401-462-1300

Spanish: 401-462-1500

TDD: 401-462-3363

#### **Medical Assistance Benefits**

*The following benefits are covered by the Medical Assistance Program for eligible children:*

- Physician's office visits
- Prescription drugs
- Medical tests
- Vision care (eyeglasses, eye exams)
- In-patient hospital care
- Out-patient hospital care
- Physical therapy
- Occupational therapy
- Speech therapy
- Mental health services
- Substance abuse treatment
- Visiting nurse services
- Dental services for children

*Some Medical Assistance benefits that are covered require prior authorization by the Department of Human Services. They include the following:*

- Durable Medical Equipment
- Home-based Therapeutic Services
- Pediatric Home Care Services
- Skilled Nursing Services
- Certified Nursing Assistant Services

## Dental Services For Children

Dental Services is a Medical Assistance benefit which covers children up to 21 years of age.

### *Preventive Dental Care includes:*

- 2 cleanings per year
- Sealants
- Fillings as necessary
- X-rays

### *Other Dental Services as medically*

- necessary (most require prior approval)*
- Orthodontics

### *How to Apply for Services*

No application is necessary. Families should contact the dentist(s) in their area to see if they accept Medical Assistance coverage for payment.

## Katie Beckett Provision

This provision provides Medicaid coverage to certain children under the age of 18 who have disabling conditions and live at home. This enables children with disabilities to be cared for at home instead of in an institution.

### *Eligibility*

Certain children under the age of 18 who live at home may be eligible for Medical Assistance benefits/coverage through the Katie Beckett provision. The cost of care provided at home must be less than what Medical Assistance would pay if the child was in a hospital or other institutional setting. Parents' resources are not counted when determining a child's eligibility.

### *How to Apply for Services*

If the child requires medical supports (oxygen, feeding tubes, monitors, frequent or lengthy hospitalizations), apply to: Rhode Island Department of Human Services, Long Term Care Unit. See the next page or [www.dhs.state.ri.us](http://www.dhs.state.ri.us) for the DHS' local office directory, under "Program: Long Term Care."

## Department of Human Services, Local Offices

When applying for Katie Beckett/Medicaid Assistance applicants should call their local DHS Office for their town.

### *Providence and North Providence*

Providence Regional Family Center  
206 Elmwood Avenue  
Providence, RI 02909  
Phone: 401-222-7000  
Fax: 401-222-7372

### *Bristol, Jamestown, Little Compton,*

*Middletown, Newport, Portsmouth, Tiverton*  
Newport Family Center  
110 Enterprise Center  
Newport, RI 02840  
Phone: 401-849-6000  
Fax: 401-849-9066

### *Charlestown, Coventry, Cranston, East*

*Greenwich, Exeter, Foster, Hopkinton,*  
*Johnston, Narragansett, New Shoreham,*  
*Scituate, Richmond, South Kingstown,*  
*Warren, Westerly, West Warwick, Warwick,*  
*West Greenwich*  
Benjamin Rush Building  
55 Howard Avenue  
Cranston, RI 02920  
Phone: 401-462-5182  
Fax: 401-462-3034

### *Burrillville, Cumberland, Glocester, Lincoln,*

*North Smithfield, Smithfield, Woonsocket*  
Woonsocket Family Center  
450 Clinton Street  
Woonsocket, RI 02895  
Phone: 401-235-6300  
Fax: 401-235-6479

### *Barrington, East Providence, Central Falls,* *Pawtucket*

Benjamin Rush Building  
55 Howard Avenue  
Cranston, RI 02920  
Phone: 401-462-5248  
Fax: 401-462-5255



## Supplemental Security Income (SSI)

This is a federal program that provides monthly cash benefits to individuals, including children with a physical, developmental and/or mental impairment that results in "marked and severe functional limitations." If a child is eligible for Supplemental Security Income (SSI) benefits in RI, he/she is also eligible to receive Medical Assistance benefits.

### *Eligibility*

Children under the age of 18 with a physical, developmental and/or mental impairment may be eligible if their family also qualifies based on limited income and resources. After the age of 18, SSI benefits are based only on the income of the individual applying for SSI.

### *How to Apply for Services*

Call or visit the local Social Security Office. Information is available by phone in both English and Spanish.

District Manager

Social Security Office

380 Westminister Street, Room 318

Providence, RI 02903

Phone: 401-528-4535 or 800-772-1213

Fax: 401-528-4698

### *Regional Offices*

55 Broad Street

Pawtucket, RI 02860

Phone: 401-724-9611 or 800-772-1213

30 Quaker Lane, 1st Floor

Warwick, RI 02886-0111

Phone: 401-822-1463 or 800-772-1213

Post Office Building

127 Social Street

Woonsocket, RI 02895

380 Westminister Mall, Room 318

Providence, RI 02903

Phone: 401-528-4501 or 800-772-1213

130 Bellevue Avenue

Newport, RI 02840

## Durable Medical Equipment

A benefit in the Medical Assistance Program available for children from birth to 21 years of age if medically necessary.

Durable Medical Equipment (DME) is equipment or devices used for medical/rehabilitative purposes in the home or community. Prior authorization is required.

### *Examples of Durable Medical Equipment include:*

- Wheelchairs
- Walkers
- Specialized strollers
- Crutches
- Hospital beds
- Feeding chairs
- Portable ramps
- Oxygen and home-based therapy equipment
- Assistive technology
- Cardiac monitors
- Hearing aids
- Apnea monitors

### *Devices Not Covered by RI Medical Assistance Program*

- Devices or equipment permanently attached to a structure
- Air conditioners
- Swimming pools
- Whirlpools

### *How to Apply for Services*

For children on Medical Assistance, families can call a durable medical equipment vendor who participates in the RI Medical Assistance Program. The vendor will evaluate the child's need and coordinate getting the necessary documentation to the Department of Human Services for review and approval.

### **Tech ACCESS Center of Rhode Island**

Tech ACCESS of RI is a private, not for profit resource center that serves people with disabilities who are interested in assistive technology. Assistive Technology is any device that helps a person with a disability function better at home, work, school, or in the community. Information and Referral Services regarding assistive technology products, funding, and services are provided at no charge. Tech ACCESS also provides referrals to service providers, vendors, protection and advocacy services, etc.

100 Jefferson Boulevard  
Warwick, RI 02888  
Voice/TYY: 800-916-8324  
Fax: 401-463-3433  
techaccess@techaccess-ri.org  
www.techaccess-ri.org

### **Rhode Island Assistive Technology Access Partnership**

Office of Rehabilitation Services  
40 Fountain Street  
Providence, RI 02903  
Phone: 401-421-7005 x310  
TYY: 401-421-7016  
Fax: 401-421-9259  
Website: www.atap.state.ri.us  
Cambodian: 401-272-7990  
Spanish: 401-272-8090

### **Adaptive Equipment Recycling Program**

The Adaptive Equipment Recycling Program at PARI provides adaptive equipment to those unable to afford new equipment. They receive used equipment by donation, restore it to useful condition, modify/adapt it according to need, and then offer the recycled product at reasonable cost to the consumer. The PARI Adaptive Equipment Recycling Programs inventory often includes wheelchairs, walkers, quad canes, forearm/platform/auxiliary crutches, lap boards, slide boards, tub transfer chairs, Gerry chairs, bedside tables, commode frames, shower chairs, bathroom safety equipment, and hearing aids.

PARI Independent Living Center  
500 Prospect Street  
Pawtucket, RI 02860  
Voice/TDD: 401-725-1966  
Fax: 401-725-2104

### **Adaptive Telephone Loan Equipment Program (ATEL)**

The ATEL Program loans telephone equipment to residents of the State of Rhode Island who have hearing, speech, or neuromuscular (unable to dial or hold a receiver) impairments. To receive equipment the person must be a resident of Rhode Island, have a speech, hearing, or neuromuscular impairment, and have a single party telephone line. A certificate of disability must be completed and signed by a doctor, a qualified staff member of the Office of Rehabilitation Services, a speech pathologist, an audiologist, or a qualified staff member of the RI School for the Deaf (if the applicant attends or has attended the school).

Stacey A. Conca-Monfils, Program Coordinator  
Adaptive Telephone Loan Equipment Program (ATEL)  
Vocational Resources, Inc.  
100 Houghton Street  
Providence, RI 02904  
Phone: 401-861-6677 or 401-861-2080  
Fax: 401-454-0889

### **National Technical Assistance Center (NTACT)**

www.nasmhpd.org/ntac

**Adaptive Environments Center, Inc.**

374 Congress Street, Suite 301

Boston, MA 02210

Voice/TTY: 617-695-0085 or 800-949-4232

Fax: 617-482-8099

[adaptive@adaptenv.org](mailto:adaptive@adaptenv.org)

[www.adaptenv.org](http://www.adaptenv.org)

**CEDARR (Comprehensive Evaluation, Diagnosis, Referral and Re-evaluation)**

Mission: All Rhode Island children and their families have an evolving, family-centered, strength based system of care, dedicated to excellence, so they can reach their full potential and thrive in their own communities.

CEDARR Family Centers offer families information on specific disabilities, treatment options and referrals to community supports and assistance.

*CEDARR Family Centers***About Families**

32 Branch Avenue

Providence, RI 02904

401-331-2700

**Family Solutions**

134 Thurbers Avenue, Suite

102

Providence, RI 02905

401-461-4351 or 800-640-

7283

**Families First**

Hasbro Children's Hospital,

Room 120

593 Eddy Street

Providence, RI 02903

401-444-7703

**Easter Seals**

5 Woodruff Avenue

Narragansett, RI 02882

401-284-1000

**Home-Based Therapeutic Services**

Home-Based Therapeutic Services are a Medical Assistance benefit that provides intense, individualized services to children with severe behavioral health and/or developmental disorders. Services are individualized and are provided in the child's home and community by trained professionals.

*How to Apply for Services*

Apply for HBTS through CEDARR Centers. See above.

**General Health Resources**

This section contains resources available to everyone via the Internet or phone. Many of these are nationwide agencies.

**American Academy of Pediatrics,  
RI Chapter**

[www.riaap.org](http://www.riaap.org)

**Centers for Disease Control**

[www.cdc.org](http://www.cdc.org)

**Dr. Koop's Community**

[www.drkoop.com](http://www.drkoop.com)

**HealthAnswers**

[www.healthanswers.com](http://www.healthanswers.com)

**Healthatoz**

Search engine for health and medicine

[www.healthatoz.com](http://www.healthatoz.com)

**Healthfinder**

Gateway consumer health information  
website from the US government

[www.healthfinder.gov](http://www.healthfinder.gov)

**HealthGate**

[www.3healthgate.com](http://www.3healthgate.com)

**Joint Commission on  
Accreditation of HealthCare  
Organizations (JCAHO)**

[www.jcaho.org](http://www.jcaho.org)

**Lifespan**

[www.lifespan.org](http://www.lifespan.org)

**Medline Fool!**

[www.medportal.com](http://www.medportal.com)

**Medline Plus Health Information**

[www.nlm.nih.gov/medlineplus](http://www.nlm.nih.gov/medlineplus)

**MedSeek**

[medseek.com](http://medseek.com)

**National Institutes of Health (NIH)**

[www.nih.gov](http://www.nih.gov)

**RI Department of Business  
Regulation, Insurance  
Regulation Division**

233 Richmond Street

Providence, RI 02903

Phone: 401-222-2223

[www.dbr.state.ri.us](http://www.dbr.state.ri.us)

**Sexual Health Network**

[sexualhealth.com](http://sexualhealth.com)

## Prescription Medication Information

### CenterWatch

Clinical trials listing service  
www.CenterWatch.com

### Pain.com

Information on pain management  
www.pain.com

### RxList

www.rxlist.com

### Affording Care: Free Medications

www.thebody.com/afford/free.html

### Directory of Prescription Drug Patient Assistance Programs

www.phrma.org/patients

### The Medicine Program

www.medicinprogram.com

### Needy Meds

Pharmaceutical manufacturer's drug assistance programs  
www.needymeds.com

### RxAssist

Obtain comprehensive information on pharmaceutical manufacturers' drug assistance programs.  
www.rxassist.org

### RIte Care

RIte Care is Rhode Island's Medicaid managed care program that provides health insurance to eligible uninsured pregnant women, parents and children up to age 19. Families receive their health care through participating Health Plans. RIte Care's participating Health Plans include: Neighborhood Health Plan of Rhode Island; Blue CHiP; and United Healthcare of New England.

#### Eligibility

Eligibility is based on family size and income.

- Pregnant women with family incomes less than 350% of the federal poverty level
- Families with children up to age 18 with family incomes less than 185% of the federal poverty level
- Children younger than 19 with family incomes less than 250% of the federal poverty level

#### Enrollment of Children with Special Needs into RIte Care

Many children with special needs who have Medical Assistance coverage (Medicaid) currently receive services through Medicaid "Fee-For-Service." This means that the Medical Assistance Program pays providers for each covered service or benefit. Most children with special needs are eligible for Medical Assistance (Medicaid) if they are found eligible for one of the following:

- SSI (Supplemental Security Income)
- Katie Beckett (a special provision in Medicaid)
- DCYF adoption subsidy

Some children with special needs who are currently receiving Medicaid "Fee-For-Service" will be enrolled in RIte Care, Rhode Island's Medicaid managed care program, in the near future.

#### Cost to Child or Family

Cost-sharing applies for children and pregnant women whose gross family income is greater than 185% of the federal poverty level.

#### Federal Poverty Level Guidelines (Annual Gross based on 2003 FPL)

	100%	120%	133%	135%	150%	175%	185%	200%
1	8,980.00	10,776.00	11,943.40	12,123.00	13,470.00	15,715.00	16,613.00	17,960.00
2	12,120.00	14,544.00	16,119.60	16,362.00	18,180.00	21,210.00	22,422.00	24,240.00
3	15,260.00	18,312.00	20,295.80	20,601.00	22,890.00	26,705.00	28,231.00	30,520.00
4	18,400.00	22,080.00	24,472.00	24,840.00	27,600.00	32,200.00	34,040.00	36,800.00
5	21,540.00	25,848.00	28,648.20	29,079.00	32,310.00	37,695.00	39,849.00	43,080.00
6	24,680.00	29,616.00	32,824.40	33,318.00	37,020.00	43,190.00	45,658.00	49,360.00
7	27,820.00	33,384.00	37,000.60	37,557.00	41,730.00	48,685.00	51,467.00	55,640.00
8	30,960.00	37,152.00	41,176.80	41,796.00	46,440.00	54,180.00	57,276.00	61,920.00

For family units of more than 8 members, add \$3,140 for each additional member.

*How to Apply for Services*

1. Visit a local Department of Human Services (DHS) office.
2. Apply by mail. To get an application call the numbers listed below.

**Rhode Island Department of  
Human Services, Center for  
Child and Family Health**

English: 401-462-1300  
Spanish: 401-462-1500  
TDD: 401-462-3363

**RItE Care Health Plan, Member  
Services**

English: 401-462-1300  
Spanish: 401-462-1500

**Neighborhood Health Plan of  
Rhode Island**

Beth Marootian  
Neighborhood Health Plan of RI  
401-459-6000 or 800-963-1001

**United Healthcare of New  
England**

Sandi Ferretti, United Healthcare of  
New England  
401-737-6900 or 800-587-5187

**Coordinated Health Partners,  
Inc. (Blue CHiP)**

Luisa Valencia  
Coordinated Health Partners, Inc.  
401-459-5504 or 800-564-0888

**RItE Share Health Insurance** (Premium Assistance Program)

Helps low and middle income families obtain health insurance coverage through their employer by paying all or part of the employee's share of monthly premiums. Under the RItE Share program, individuals who are income eligible for Medical Assistance and are employed by an employer who offers an approved health plan can enroll in their employer's health insurance plan. The RItE Share program will also pay all or part of co-payments associated with the employer's health plan.

*Eligibility*

- Pregnant women whose annual income is below 250% of the Federal Poverty Level (FPL)
- Children (birth to age 19) whose family's annual income is below 250% of the FPL
- Families with children under age 18 whose income is below 185% of the FPL

*How to Apply for Services*

1. Visit a local Department of Human Services (DHS) office; See page 21 **or**
2. Apply by mail. To get an application call the numbers listed below.

**Rhode Island Department of Human Services  
Center for Child and Family Health**

600 New London Avenue  
Cranston, RI 02920  
English: 401-462-1300  
Spanish: 401-462-1500  
TDD: 401-462-3363

## Specific Disorders and Disabilities

In this section we have listed many resources that are available to families about genetic disorders, birth defects, and disabilities. The Internet is a great tool to search for information. If you don't have a computer, all of the libraries in Rhode Island have computers for public use. If you have questions on something we haven't covered please call Family Voices of Rhode Island at 401-727-4144 x162 for assistance.

### Allergies and Asthma

*Asthma and Allergy Foundation of America*  
1233 20th Street, N.W., Suite 402  
Washington, DC 20036  
Phone: 202-466-7643 or 800-727-8462  
Fax: 202-466-8940  
[www.aafa.org](http://www.aafa.org)

*Draw a Breath Program*  
Hasbro Children's Hospital  
593 Eddy Street  
Providence, RI 02903  
Phone: 401-444-8340  
[www.drawabreath.com](http://www.drawabreath.com)

### Attention Deficit/Hyperactivity Disorder

*Children and Adults with Attention-Deficit/Hyperactivity Disorder (CHADD)*  
8181 Professional Place, Suite 201  
Landover, MD 20785  
Phone: 301-306-7070 or 800-233-4050 (Voice mail to request information packet)  
[national@chadd.org](mailto:national@chadd.org)  
[www.chadd.org](http://www.chadd.org)

*National Attention Deficit Disorder Association (ADDA)*  
PO Box 1303  
Northbrook, IL 60065-1303  
[mail@add.org](mailto:mail@add.org)  
[www.add.org](http://www.add.org)

### Autism/Asperger's Syndrome

*Autism Network International (ANI)*  
ANI was founded by people with autism for people with autism. There is a membership fee of \$15 per year.  
PO Box 35448  
Syracuse, NY 13235-5448  
[ani.autistics.sorg](http://ani.autistics.sorg)

*Autism Society of America (ASA)*  
7910 Woodmont Avenue, Suite 300  
Bethesda, MD 20814  
Phone: 301-657-0881 or 800-3-AUTISM  
Fax: 800-FAX-0899  
[www.autism-society.org](http://www.autism-society.org)

*Autism Research Institute (ARI)*  
ARI publishes the Autism Research Review International. This quarterly review is available for \$18 per year.  
4182 Adams Avenue  
San Diego, CA 92116  
Phone: 619-281-7165  
Fax: 619-563-6840  
[www.autism.com/ari](http://www.autism.com/ari)

*Autism Society of Rhode Island (ASRI)*  
ASRI hosts monthly meetings from September through June. ASRI also provides conferences, speakers, a resource center, and a newsletter.  
Gateway Plaza, Suite 204  
1645 Warwick Avenue  
Warwick, RI 02889

*Online Asperger Syndrome Information and Support (OASIS)*  
[www.udel.edu/bkirby/asperger/frame2.html](http://www.udel.edu/bkirby/asperger/frame2.html)

### Brain Injury

*Brain Injury Association of RI*  
*Independent Square*  
500 Prospect Street  
Pawtucket, RI 02860  
Phone: 401-725-2360  
[BuckleUp1@aol.com](mailto:BuckleUp1@aol.com)  
[www.biausa.org](http://www.biausa.org)

*Health-Helper*  
Brain injury, concussion and health resources  
[www.health-helper.com](http://www.health-helper.com)

*BrainTalk Communities*  
Online patient support groups for neurology  
[neuro-mancer.mgh.harvard.edu/cgi-bin/Ultimate.cgi](http://neuro-mancer.mgh.harvard.edu/cgi-bin/Ultimate.cgi)

## **Cancer**

*American Cancer Society*  
1599 Clifton Road NE  
Atlanta, GA 30329-4251  
Phone: 404-320-3333 or 800-227-2345  
[www.cancer.org](http://www.cancer.org)

## **Cerebral Palsy**

*United Cerebral Palsy of RI (UCP)*  
Christiane Petrin Lambert, Executive Director  
200 Main Street, Suite 210  
PO. Box 36  
Pawtucket, RI 02862  
Phone: 401-728-1800  
Fax: 401-728-0182  
[www.ucpri.org](http://www.ucpri.org)

## **Deaf-Blind**

*National Family Association for Deaf-Blind*  
111 Middle Neck Road  
Sandy Point, NY 11050-1129  
Phone: 800-255-0411 x 275  
TTY: 516-944-8637  
Fax: 516-944-7302  
[www.helenkeller.org.national](http://www.helenkeller.org.national)

## **Developmental Disabilities**

*Blackstone Valley Chapter RIARC*

The Blackstone Valley Chapter provides services and support to persons with mental retardation and their families. The Center assists individuals in making decisions and taking responsibility for their lives, and helps the community learn about the abilities and potential of citizens with mental retardation. Program services include:

- Living (residential) support
- Employment support
- Personal Wellness Support
- Community Inclusion Support
- Vocational Evaluation
- Community Resource Identification and Access
- Educational Services
- Speech and Language Services
- Nursing Services
- Behavioral/Psychosocial Services
- Physical Therapy Services
- Nutritional and related health services
- Community Recreational Services and Supports

Peter Holden, Executive Director  
115 Manton Street  
Pawtucket, RI 02861  
Phone: 401-727-0150  
Fax: 401-727-0153  
Email: [contact@bvcriarc.org](mailto:contact@bvcriarc.org)  
[www.bvcriarc.org](http://www.bvcriarc.org)

#### *Cranston Arc*

The mission of Cranston Arc (formerly the Cranston Center) is to empower people with differing abilities to claim and enjoy their rights to dignity and respect. The Arc believes everyone has abilities and can be a participating member of society. Cranston Arc provides social, recreational, and vocational services for children and adults with developmental disabilities including day programs, residential programs, respite programs, and recreational activities.

Thomas Kane, Executive Director

905 Pontiac Avenue

Cranston, RI 02920

Phone: 401-941-1112 or 401-942-3445

[www.cranstonarc.org](http://www.cranstonarc.org)

#### *RI Arc*

James Healey, Executive Director

99 Bald Hill Road

Cranston, RI 02920

Phone: 401-463-9191

Fax: 401-463-9244

[Riarc@compuserve.com](mailto:Riarc@compuserve.com)

#### *The Arc of the US*

[www.TheArc.org](http://www.TheArc.org)

### **Diabetes**

#### *American Diabetes Association - National Service Center*

1660 Duke Street

Alexandria, VA 22314

Phone: 703-549-1500 or 800-342-2383

Fax: 703-549-6995

[www.diabetes.org](http://www.diabetes.org)

### **Down Syndrome**

#### *Down Syndrome Society of RI*

Claudia M. Lowe

Jeffery DiMillio

99 Bald Hill Road

Cranston, RI 02920

Phone: 401-463-5751

[dssri@aol.com](mailto:dssri@aol.com)

### **Epilepsy**

#### *American Epilepsy Society*

638 Prospect Avenue

Hartford, CT, 06105-4240

Phone: 860-586-7505

Fax: 860-586-7550

[www.aesnet.org](http://www.aesnet.org)

#### *Epilepsy Foundation of America*

4351 Garden City Drive

Landover, MD 20785-2267

Phone: 301-459-3700 or 800-332-

4050

Fax: 301-577-2684

[www.efa.org](http://www.efa.org)

#### *Epilepsy Foundation of Massachusetts and Rhode Island*

William Murphy, Executive Director

95 Berkeley Street, Suite 409

Boston, MA 02116

Phone: 617-542-2292 or 888-576-9996

[ne-index.shriver.org/Factsweb/](http://ne-index.shriver.org/Factsweb/)

2206.htm



## Genetic Disorders

*Alliance of Genetic Support Groups*  
4301 Connecticut Avenue  
Washington, DC 20008-2304  
Phone: 202-966-5557 or 800-336-GENE  
Fax: 202-966-8553  
[www.geneticalliance.org](http://www.geneticalliance.org)

*National Organization for Rare Disorders (NORD)*  
100 Rt. 37  
PO Box 8923  
New Fairfield, CT 06812-8923  
Phone: 203-746-6518 or 800-999-6673  
[www.rarediseases.org](http://www.rarediseases.org)

*MUMS: National Parent to Parent Network*  
Julie J. Gordon  
150 Custer Court  
Green Bay, Wisconsin 54301-1243  
Phone: 920-336-5333 or 877-336-5333 (Parents only please)  
Fax: 920-339-0995  
[mums@netnet.net](mailto:mums@netnet.net)  
[www.netnet.net/mums](http://www.netnet.net/mums)

## Hearing Impairment

*National Association of the Deaf (NAD)*  
814 Thayer Avenue  
Silver Spring, MD 20910-4500  
Phone: 301-587-1788  
TTY: 301-587-1789  
Fax: 301-587-1791  
[www.nad.org](http://www.nad.org)

*Alexander Graham Bell Association for the Deaf and Hard of Hearing*  
3417 Volta Place, N.W.  
Washington, DC 20007-2778  
Phone and TTY: 202-337-5220  
Fax: 202-337-8314  
[www.agbell.org](http://www.agbell.org)

*American Society for Deaf Children*  
P.O. Box 3355  
Gettysburg, PA 17325  
Phone and TTY: 717-334-7922  
Fax: 717-334-8808  
[www.deafchildren.org](http://www.deafchildren.org)

*First Connections - Training Resource Project for Newborn Screening*  
Mary Jane Johnson  
One Corliss Park  
Providence, RI 02908  
Phone: 401-222-4013  
Fax: 401-222-6998

*Relay RI*  
Provides for communications between individuals using TTY devices and persons using regular telephones.  
Phone: 800-745-6575 or 711 for easy access  
TTY: 800-745-5555  
Spanish Phone: 800-855-2885  
Spanish TTY: 800-855-2884  
AT&T Operator for the Deaf (OSD): 800-855-1155  
Relay Consumer Service Number: 800-682-8706 Voice; 800-682-8786 TTY

*Rhode Island Association of the Deaf (RIAD)*  
Provides support and active advocacy for Deaf and Hard of Hearing citizens of Rhode Island. RIAD is an affiliated member of the National Association of the Deaf (NAD), one of the oldest and largest consumer organizations for disabled persons in the US.  
Maria G. Okwara, President  
PO Box 40853  
Providence, RI 02940  
TDD: 401-431-0465  
Relay: 800-745-6575  
[EarnestO@aol.com](mailto:EarnestO@aol.com)  
[members.aol.com/Earnesto/RIAD.html](http://members.aol.com/Earnesto/RIAD.html)

*RI Commission on the Deaf and Hard of Hearing*  
One Capitol Hill, Ground Floor  
Providence, RI 02906  
TTY: 401-222-1205  
Fax: 401-222-5736  
[slane@doa.state.ri.us](mailto:slane@doa.state.ri.us)

*RI DeafWorldWeb*  
[www.deafworldweb.org/int/us/ri](http://www.deafworldweb.org/int/us/ri)

*RI Speech-Language-Hearing Association*  
Eve Evans Sadd, President  
PO Box 9241  
Providence, RI 02940  
Phone: 401-438-9500  
[sadd@uri.edu](mailto:sadd@uri.edu)  
[professional.asha.org/states/rhodeisland.htm](http://professional.asha.org/states/rhodeisland.htm)

*Self Help for the Hard of Hearing (SHHH): RI Chapter*  
Sargent Rehabilitation Center  
2nd Floor Conference Room  
229 Waterman St.  
Providence, RI 02905  
Phone: 401-751-3113  
[shhhsargents@usa.com](mailto:shhhsargents@usa.com)  
[www.shhhsargents.homestead.com/index.html](http://www.shhhsargents.homestead.com/index.html)

## Heart Disorders

*American Heart Association*

7272 Greenville Avenue

Dallas, TX 75231-4596

Phone: 214-706-1176 or 800-242-8721

Fax: 214-706-2139

[www.amhrt.org](http://www.amhrt.org)

## HIV/AIDS

*HIV/AIDS in Rhode Island (including anonymous & confidential testing sites)*

[www.doh.state.ri.us/disprev/communcable/hiv\\_aids.htm](http://www.doh.state.ri.us/disprev/communcable/hiv_aids.htm)

*AIDS Care Ocean State*

18 Parkis Avenue

Providence, RI 02907

Phone: 401-521-3603

Fax: 401-861-2981

[aidscaresos.org](http://aidscaresos.org)

*AIDS Project RI*

232 West Exchange Street

Providence, RI 02906

Hotline: 800-726-3010

Phone: 401-831-5522

TDD: 401-831-5693

Fax: 401-454-0299

[www.aidsprojectri.org](http://www.aidsprojectri.org)

[aprihotline@hotmail.com](mailto:aprihotline@hotmail.com)

*National Pediatric and Family HIV Resource Center*

30 Bergen Street, ADMC-4

Newark, NJ 07107

Phone: 973-972-0410 or 800-362-0071

Fax: 973-972-0399

[www.wdcnet.com/pedsaids](http://www.wdcnet.com/pedsaids)

## Learning Disabilities

*Literacy Volunteers of America/RI*

Donna Sherman

260 West Exchange Street, Suite 106

Providence, RI 02903

Phone: 401-861-0815

*National Adult Literacy & Learning Disabilities Center (NALLD)*

Academy for Educational Development

1875 Connecticut Avenue, NW

Washington, DC 20009-1202

Phone: 202-884-8185 or 800-953-ALLD (800-953-2553)

Fax: 202-884-8429

[www.ld-read.org](http://www.ld-read.org)

**Mental/Behavioral Health** (For information, see page 36)

## Multiple Sclerosis

*National Multiple Sclerosis Society, RI Chapter*  
Gwen Norwood Reeve, Program Director  
205 Hallene Road  
Warwick, RI 02886  
Phone: 401-738-8383  
[www.nmssri.org](http://www.nmssri.org)

## Rare Disorders and Diseases

*Search and Respond*  
c/o Exceptional Parent Magazine  
555 Kinderkamack Road  
Oradell, NJ 07649-1517  
Phone: 202-634-6550  
Fax: 202-634-6570  
[www.eparent.com](http://www.eparent.com)

*National Organization for Rare Disorders (NORD)*  
100 Route 37  
PO Box 8923  
New Fairfield, CT 06812-8923  
Phone: 203-746-6518 or 800-999-6673  
[www.rarediseases.org](http://www.rarediseases.org)

## Speech Disorders

*RI Speech-Language-Hearing Association*  
Eve Evans Sadd, President  
PO Box 9241  
Providence, RI 02940  
Phone: 401-438-9500  
[sadd@uri.edu](mailto:sadd@uri.edu)  
[professional.asha.org/states/rhodeisland.htm](http://professional.asha.org/states/rhodeisland.htm)

## Spina Bifida

*Spina Bifida Association of RI*  
Deborah Gellman, President  
PO Box 6948  
Warwick, RI 02887  
Phone: 401-732-7862  
[DAHLIADEBZ@aol.com](mailto:DAHLIADEBZ@aol.com)  
[www.sbaa.org](http://www.sbaa.org)

## Transverse Myelitis

*Transverse Myelitis Information*  
[www.myelitis.org](http://www.myelitis.org)

## Visual Impairments

*American Foundation for the Blind*  
Regine Genwright, Director of Information Center  
11 Penn Plaza, Suite 300  
New York, NY 10001  
Phone: 212-502-7600 or 800-726-3010  
TTY: 212-502-7662  
[afbinfo@afb.org](mailto:afbinfo@afb.org)  
[www.afb.org](http://www.afb.org)

*IN-SIGHT Programs in Productive Living for the Blind*  
A private, non-profit organization incorporated in 1925 to serve the needs of Rhode Island's blind and visually-impaired population of all ages. IN-SIGHT gives people the opportunity to lead more mobile, independent, and productive lives.  
Judith Smith, President  
43 Jefferson Boulevard  
Warwick, RI 02888  
Phone: 401-941-3322

### *IN-SIGHT Radio*

A non-profit, non-commercial, closed circuit radio reading service for the blind and print-handicapped of Rhode Island and surrounding areas. IN-SIGHT RADIO provides current printed material (newspapers, magazines, books) to listeners who are unable to use printed materials due to a visual or a physical disability. Half of each broadcast day consists of readings taken from national, state and local newspapers. Emphasis is given to features that are unique to a newspaper such as food advertisements, editorials, death notices, and columns. IN-SIGHT RADIO also offers a variety of special interest programs focusing on consumerism, health, retirement concerns, and entertainment listings. In addition, the programs are delivered to homes through four cable television systems. To be eligible for IN-SIGHT RADIO a person must have a visual or physical handicap that prevents him or her from reading conventional printed material.

43 Jefferson Boulevard

Warwick, RI 02888

Phone: 401-941-3322

### *National Library Service for the Blind and Physically Handicapped*

[lcweb.loc.gov/nls/nls.html](http://lcweb.loc.gov/nls/nls.html)

### *OSCIL Sign Language Interpreter Referral Service*

Requests for an interpreter should be made at least two weeks in advance. Be sure to leave the following information with the referral service: agency name, address, telephone number and contact person; date interpreter is needed; location, time and length, and nature of event for which the interpreter is needed; type of sign language interpreter preferred by consumer (ASL, Signed English, Oral).

Phone: 800-525-0770

TDD: 800-232-0438

[www.oscil.org](http://www.oscil.org)

### *Services for the Blind and Visually Impaired (SBVI)*

The purpose of Services for the Blind and Visually Impaired is to provide eligible individuals with visual impairments the opportunities and support that will enable them to become independent, active, self-sustaining members of their communities.

Office of Rehabilitation Services

40 Fountain Street

Providence, RI 02903

Phone: 401-222-2300 or 800-752-8088 x2300

TDD: 401-222-3010

Cambodian: 401-272-7990

Spanish: 401-272-8090

Fax: 401-222-1328

[www.ors.state.ri.us/sbvipage.htm](http://www.ors.state.ri.us/sbvipage.htm)

### *Talking Books Plus: RI Regional Library for the Blind and Physically Handicapped*

The Regional Library serves as a public library for eligible persons residing in Rhode Island by loaning special reading materials and equipment free of charge. Books recorded on cassettes as well as large print and Braille books are mailed postage free to individuals qualifying for this service. Special cassette and talking book machines specifically designed for use with the recorded materials are issued along with the materials. All of the services mentioned are available to persons of any age who qualify on the basis of a visual or physical handicap that prevents them from using conventional print materials, and who can provide certification by a competent authority. Regional Libraries are located in all states in the United States. The National Library Service for the Blind and Physically Handicapped (NLS), a program sponsored by the Library of Congress, provides all talking books and the equipment on which they are played.

Andrew Egan, Supervisor

Office of Library and Information Services

One Capitol Hill

Providence, RI 02908

Phone: 401-222-5800 or 800-734-5141 (in-state)

[tbplus@lori.state.ri.us](mailto:tbplus@lori.state.ri.us)

[www.ori.state.ri.us/TBP/default.htm](http://www.ori.state.ri.us/TBP/default.htm)

#### *Vision Services Program*

The Vision Services Program provides services to children who are blind or visually impaired.

Contact

Claire Irwin

Vision Services Program

1 Corliss Park

Providence, RI 02908

Phone: 401-222-3827

#### *Rhode Island Services for Children and Youth with Dual Sensory Impairment*

This federally funded project provides training and technical assistance related services to children and youth with dual sensory impairments (vision and hearing impairments). Dual sensory impairments means having both auditory and visual impairments that create such severe communication and other developmental and learning needs that they cannot be appropriately educated without special education and related services.

Dr. Susan Dell, Project Coordinator

Rhode Island Services for Children and Youth with Dual Sensory Impairment

Sherlock Center on Disabilities

Rhode Island College

600 Mount Pleasant Avenue

Providence, RI 02908

Phone: 401-456-8072

Fax: 401-456-8150

## **Hospitals**

#### *Hasbro Children's Hospital*

593 Eddy Street

Providence, RI

Phone: 401-444-4000

#### *Boston Children's Hospital*

300 Longwood Avenue

Boston, MA 02115

Phone: 617-732-5500

#### **Providence Ronald McDonald House**

Provides a home-away-from-home for families of children receiving treatment at local hospitals, primarily Women & Infants, Hasbro Children's and Bradley Hospitals. Families of pregnant women in need of prolonged hospitalization and families of premature infants also are welcome at the House.

45 Gay Street

Providence, RI 02905

Phone: 401-274-4447

Fax: 401-751-3730

[prmh@tiac.net](mailto:prmh@tiac.net)

[www.rmhc.com](http://www.rmhc.com)

## **Psychiatric Hospitals**

#### *Arbour-Fuller Hospital*

200 May Street

South Attleboro, MA

Phone: 401-761-8500

[www.arbourhealth.com](http://www.arbourhealth.com)

#### *Bradley Hospital*

A psychiatric center for children, adolescents, and their families. Also provides in-home services.

1011 Veterans Memorial Parkway

East Providence, RI 02915

Phone: 401-432-1000

#### *Butler Hospital*

345 Blackstone Boulevard

Providence, RI 02906

Phone: 401-455-6200

## **Shriner's Hospitals**

#### *Boston Shriner's Hospital, Burn Center*

51 Blossom Street

Boston, MA 02114

Phone: 617-722-3000

#### *Springfield Shriner's Hospital, Orthopedic*

516 Carew Street

Springfield, MA

Phone: 413-787-2000

[www.shrinershq.org](http://www.shrinershq.org)

## Therapy Services

This includes resources for Occupational, Physical, Speech, Social Skills and Therapeutic Recreation.

### *Rehab New England*

Rehab New England provides occupational and physical therapy, and speech pathology services to children birth-21 years old. In-home services are provided as well.

120 Lambert Street  
Warwick, RI 02886  
Phone: 401-739-5900

### *Meeting Street Center*

667 Waterman Avenue  
East Providence, RI 02914  
Phone: 401-438-9500

### *AOTA- American Occupational Therapy Association*

4720 Montgomery Lane  
PO Box 31220  
Bethesda, MD 20824-1220  
Phone: 301-652-2682  
[www.aota.org](http://www.aota.org)

### *RI Occupational Therapy Association*

PO Box 40203  
Providence, RI 02940-0203  
Phone: 401-726-8473

### *American Physical Therapy Association*

[www.apta.org](http://www.apta.org)

### *RI American Physical Therapy Association*

Phone: 401-874-5391

### *RI Speech-Language-Hearing Association*

Eve Evans Sadd, President  
PO Box 9241  
Providence, RI 02940  
Phone: 401-438-9500  
[sadd@uri.edu](mailto:sadd@uri.edu)  
[professional.asha.org/states/rhodeisland.htm](http://professional.asha.org/states/rhodeisland.htm)

## Therapeutic Recreation

### *Boys and Girls Clubs of Providence*

33 Atwood Street  
PO Box 3270-09  
Providence, RI 02909  
Phone: 401-444-0750  
Fax: 401-444-0757

### *Boy Scouts of America*

Narragansett Council  
175 Broad Street  
Providence, RI 02903-4081  
Phone: 401-351-8700  
[www.narragansettbsa.org](http://www.narragansettbsa.org)

### *Disabled Sports USA*

451 Hungerford Drive, Suite 100  
Rockville, MD 20850  
Phone: 301-217-0960  
Fax: 301-217-0968  
[www.dsusa.org](http://www.dsusa.org)

### *Girl Scouts of RI*

125 Charles Street  
Providence, RI 02904  
Phone: 401-331-4500  
[www.gsusa.org](http://www.gsusa.org)

### *Greenlock Therapeutic Riding Center*

55 Summer Street  
Rehoboth, MA 02769  
Phone: 508-252-5814

### *Groden Center*

86 Mount Hope Avenue  
Providence, RI 02906  
Phone: 401-274-6310

### *Impossible Dream Park*

575 Centerville Road  
Warwick, RI 02886  
Phone: 401-823-5566

### *John Hope Settlement House*

7 Burgess Street  
Providence, RI 02903  
Phone: 401-421-6993

### *Piano and Voice Lessons*

Kathy Field, B.S. Music Education  
Experience teaching children with autism.  
Phone: 401-333-9656

### *RI Family Guide- Summer Camp Directory*

PO Box 163  
Warren, RI 02885  
Phone: 401-247-0850  
[www.rifamilyguide.com](http://www.rifamilyguide.com)

### *Shake A Leg*

Provides mainstream, complimentary, and recreational therapeutic services (including adaptive sailing program) that develop independent living skills for individuals who have experienced spinal cord injury and related nervous system disorders.  
PO Box 1264  
Newport, RI 02840  
Voice: 401-849-8898  
Fax: 401-848-9072  
[www.shakealeg.org](http://www.shakealeg.org)

### *Special Olympics RI*

33 College Hill Road  
Warwick, RI 02886  
Phone: 401-823-7411  
Fax: 401-823-7415  
[www.specialolympics.org](http://www.specialolympics.org)

### *Tides Family Services*

1599 Main Street  
West Warwick, RI  
Phone: 401-831-1360

### *Tri-State Multi Services*

7 Country View Drive  
Coventry, RI  
Phone: 401-828-6210

### *Very Special Arts RI*

Jeannine Chartier, Executive Director  
500 Prospect Street  
Pawtucket, RI 02860  
Phone: 401-725-0247  
TTY: 800-745-5555 (TTY)  
[ride0057@ride.ri.net](mailto:ride0057@ride.ri.net)  
[www.vsarts.org/affiliates/states/ri.lasso](http://www.vsarts.org/affiliates/states/ri.lasso)

## Mental/Behavioral Health

### **Alliance for the Mentally Ill of RI**

1255 North Main Street  
Providence, RI 02904  
Phone: 401-331-3060  
nicknami@aol.com  
ri.nami.org

### **Department of Mental Health, Retardation & Hospitals (MHRH)**

A. Kathryn Power, Director  
14 Harrington Road  
Cranston, RI 02920  
Phone: 401-462-3201  
TDD: 401-462-6087  
Fax: 401-462-3204  
kpower@mhrh.state.ri.us  
www.mhrh.state.ri.us

### **Manic Depressive and Depressive Association of RI**

53 Lafayette Drive  
Bristol, RI 02809  
Phone: 401-254-2572

### **Mental Health Advancement Resource Center (MHARC)**

500 Prospect Street  
Pawtucket, RI 02860  
Phone: 401-726-8383  
RI Relay: 800-745-6575  
Fax: 401-726-2287  
MHARC@conversent.net  
www.mharc.com

### **Mental Health Association of RI**

Cynthia A. O'Neil, Executive Director  
500 Prospect St.  
Pawtucket, RI 02860  
Phone: 401-726-2285  
mmhari@aol.com

### **Parent Support Network**

400 Warwick Ave  
Warwick, RI 02886  
Phone: 401-467-6855 or 800-483-8844

### **Providence Community Action (ProCap)**

662 Hartford Avenue  
Providence, RI 02909  
Phone: 401-272-0660

### **RI Council of Community Mental Health Centers**

67 Cedar Street, Suite 1  
Providence, RI 02903  
Phone: 401-273-0900

## **Web Resources**

*CMHS' Knowledge Exchange Association*  
(Center for Mental Health Services)  
www.mentalhealth.org

*Mental Health Advancement Resource  
Center (MHARC)*  
www.mharc.com/home.htm

*National Alliance for the Mentally Ill,  
NAMI RI*  
ri.nami.org

*National Association of State Alcohol and  
Drug Abuse Directors (NASADAD)*  
www.nasadad.org

*National Association of State and Mental  
Health Program Directors*  
www.nasmhpd.org

*National Clearinghouse for Alcohol and  
Drug Information*  
www.health.org

*National Consumer Empowerment Center*  
www.power2u.org

*National Institute of Mental Health  
(NIMH)*  
www.nimh.nih.gov

*National Technical Assistance Center  
(NTACT)*  
www.nasmhpd.org/nt

## **Substance Abuse Resources**

*CMHS' Knowledge Exchange Association*  
www.mentalhealth.org

*HIV/AIDS in RI*  
www.doh.state.ri.us/disprev/commu-  
nicable/hiv\_aids.htm

*Manisses Communications Group*  
Information in the behavioral health field  
www.bhrpress.com/free\_reports.htm

*Mental Health Advancement Resource  
Center (MHARC)*  
www.mharc.com/home.htm

*National Alliance for the Mentally Ill,  
NAMI RI*  
www.nami.org/about/amiri

*National Association of State Alcohol and  
Drug Abuse Directors*  
www.nasadad.org

*National Association of State and Mental  
Health Program Directors (NASMHPD)*  
www.nasmhpd.org

*National Clearinghouse for Alcohol and  
Drug Information*  
www.health.org

*National Institute of Mental Health  
(NIMH)*  
www.nimh.nih.gov

*Rhode Island Council on Alcoholism and  
Other Drug Dependence Helpline*  
Phone: 401-725-0410 or 800-622-7422

*Substance-Abuse Related Communicable  
Diseases*  
www.doh.state.ri.us/disprev/commu-  
nicable/commhome.htm



## Children's Intensive Services

*Community Counseling Center*  
160 Beechwood Avenue  
Pawtucket, RI 02860  
Phone: 401-722-5573

*East Bay Mental Health Center*  
2 Old Country Road  
Barrington, RI  
Phone: 401-246-1195

*Kent County Mental Health Center*  
300 Centerville Road, Suite 301-5  
Warwick, RI 02886  
Phone: 401-732-5656

*Mental Health Services of Cranston,  
Johnston, and Northwestern RI*  
1443 Hartford Avenue  
Johnston, RI 02919  
Phone: 401-273-8100 or 888-841-5252

*Newport County Community Mental  
Health Center*  
127 Johnny Cake Hill  
Middletown, RI 02842  
Phone: 401-846-1213

*Northern RI Community Mental Health  
Center*  
Serving: Woonsocket, N. Smithfield,  
Burritville, Cumberland, Lincoln  
55 Cummings Way  
Woonsocket, RI 02895  
Phone: 401-766-3330

*The Providence Center*  
520 Hope Street  
Providence, RI 02906  
Phone: 401-276-4000

*South Shore Community Mental Health  
Center*  
4705A Old Post Road, 1A South  
Charleston, RI 02813  
Phone: 401-364-7705

## Children's Emergency Services

*Child and Family Services of Newport  
County*  
24 School Street  
Newport, RI  
Phone: 401-841-8840

*Community Counseling Center*  
160 Beechwood Avenue  
Pawtucket, RI  
Phone: 401-722-5573

*Cranston Community Action Program*  
41 Heath Avenue  
Cranston, RI  
Phone: 401-467-9610

*Family Services, Inc.*  
55 Hope Street  
Providence, RI 02906  
Phone: 401-331-1350

*John Hope Settlement House*  
7 Burgess Street  
Providence, RI 02903  
Phone: 401-421-6993

*Kent County Mental Health Center*  
300 Centerville Road, Suite 301-5  
Warwick, RI 02886  
Phone: 401-738-4300

*Mental Health Services of Cranston,  
Johnston, and Northwestern RI*  
1443 Hartford Avenue  
Johnston, RI 02919  
Phone: 401-273-8100 or 888-841-5252

*Rhode Island Youth Guidance Center*  
82 Pond Street  
Pawtucket, RI 02860  
Phone: 401-725-0450

*South Shore Community Mental Health  
Center*  
4705A Old Post Road, 1A South  
Charleston, RI 02813  
Phone: 401-364-7705

*Family Resources Community Action*  
245 Main Street  
Woonsocket, RI 02895  
Phone: 401-766-0900



## Community Mental Health Centers in Rhode Island

### *RI Council of Community Mental Health Centers*

A Community Mental Health Center in each area serves as single point of entry for services and provides:

- 24-Hour Emergency Service
  - Inpatient Services
  - Psychiatric Services
  - Medication Maintenance
  - Community Residences
  - Psychiatric Rehab, including employment
  - CPST, including help finding work and housing
  - Counseling Services
- 67 Cedar Street, Suite 1  
Providence, RI 02903  
Phone: 401- 273-0900  
Fax: 401-273-0901

### *Community Counseling Center, Inc.*

160 Beechwood Avenue  
Pawtucket, RI 02860  
Phone: 401-722-5573  
Intake: 401-723-1915

### *East Bay Mental Health Center, Inc.*

2 Old County Road  
Barrington, RI 02806  
Phone: 401-246-1195  
Intake: 401-431-9870

### *Kent County Mental Health Center, Inc.*

50 Health Lane  
Warwick, RI 02886  
Phone: 401-738-4300  
Intake: 401-738-4300

### *Mental Health Services of Cranston, Johnston and Northwestern RI, Inc.*

516 Atwood Avenue  
Johnston, RI 02919  
Phone: 401-273-8100  
Intake: 401-273-8100

### *Newport County Community Mental Health Center, Inc.*

127 Johnnycake Hill Road  
Middletown, RI 02842  
Phone: 401-846-1213  
Intake: 401-846-1213

### *Northern R.I. Community Mental Health Center, Inc.*

515 Social Street  
P.O. Box 1700  
Woonsocket, RI 02895  
Phone: 401-766-3330  
Intake: 401-762-1577

### *The Providence Center for Counseling and Psychiatric Services*

520 Hope Street  
Providence, RI 02906  
Phone: 401-276-4000  
Intake: 401-276-4020

### *South Shore Mental Health Center, Inc.*

4705A Old Post Road  
P.O. Box 899  
Charlestown, RI 02813  
Phone: 401-364-7705  
Intake: 401-364-7705

## CASSP and the Local Coordinating Council

"CASSP" stands for Child and Adolescent Service System Program, a system of care for children and youth with severe emotional disturbances. Each of eight mental health catchment areas in the state has a Local Coordinating Council, or LCC, to serve their community. The LCC is made up of representatives from mental health, social service, and recreation agencies, local education authorities, state agencies involved with child and family issues, parent advocates, and most importantly parents.

The LCC is charged with pulling together a continuum of services that meet the needs of children with serious emotional or behavioral challenges and their families in a culturally competent, community-based, child centered and family focused way. The LCCs are responsible for ensuring that services are accessible to families and, most importantly, that families are integral partners in determining the best service plans for their children.

This is accomplished through the use of planning teams composed of formal and informal supports identified by the family, family members, and a Family Service Coordinator from the LCC. The latter is an individual with experience in negotiating various service systems within the state. The Family Service Coordinator assists the family in identifying their strengths, needs, and service requests that are then brought to the planning team for the development of an individual service plan for the child and family.

### *Eligibility*

Children and Youth eligible for CASSP are:

- between the ages of birth and twenty-one (21) years;
- have a serious emotional, behavioral, or mental disorder (DSM-IV) with the exception of ("V" codes) substance abuse and developmental disorders, unless they are a co-occurring disorder with another serious emotional disturbance;
- have a disability that has been, or is potentially on-going for a period of one (1) year or more;
- are in need of multi-agency intervention; and
- are at risk for out of home or more restrictive placements due to emotional/behavioral problems.

Note: A similar program, Project Hope, exists for adjudicated youth exiting the RI Training School. Information can be obtained on project Hope by contacting any of the LCC/CASSP sites listed below.

## **CASSP/LCC Contacts**

### *Providence*

John Hope Settlement House  
7 Burgess Street  
Providence, RI 02903  
Phone: 401-421-6993  
Fax: 401-454-5619

### *Northern Rhode Island*

(Woonsocket, Cumberland, Lincoln,  
North Smithfield, Burrillville)  
Stadium Building  
1 Social Street  
Woonsocket, RI 02895

### *Pawtucket / Central Falls*

Community Counseling Center  
160 Beechwood Avenue  
Pawtucket, RI 02860  
Phone: 401-722-5573 x232  
Fax: 401-726-5571

### *Kent County*

(Warwick, West Warwick, Coventry,  
West Greenwich, East Greenwich)  
Kent County Mental Health Center  
Summit South  
300 Centerville Road, Suite 301S  
Warwick, RI 02886  
Phone: 401-732-5656  
Fax: 401-738-8634

### *Metro West*

(Cranston, Foster, Glocester, Johnston,  
Scituate, Smithfield)  
Mental Health Services of Cranston,  
Johnston, and NWRI  
311 Doric Avenue  
Cranston, RI 02910  
Phone: 401-784-3633  
Fax: 401-784-3636

### *Washington County*

(Charlestown, Exeter, Hopkinton,  
Narragansett, North Kingstown, South  
Kingstown, Richmond, Westerly, New  
Shoreham )  
South Shore Community Mental  
Health Center  
730 Kingstown Road  
Wakefield, RI 02879  
Phone: 401-789-1166  
Fax: 401-789-7035

### *Newport*

(Jamestown, Little Compton,  
Middletown, Portsmouth, Tiverton)  
CASSP Staff Supervisor  
401-848-6363

## Family Education, Advocacy, and Support

Family education, advocacy, and support programs provide informational and emotional support to families who have a child, adolescent, or adult family member with special needs. They offer an important connection for a family who is seeking support for a specific disability issue, through group discussion in support groups and in meeting other families who are further along in their journey. We have also included a section on *family fun*.

### The Rhode Island Parent Information Network

The Rhode Island Parent Information Network (RIPIN), which houses Family Voices of RI, is a statewide, non-profit organization committed to empowering, educating and encouraging families to seek positive outcomes for their children. Families and professionals seek the expertise and guidance of RIPIN staff via telephone, email, in person, or by participating in one of many training workshops. Training and parenting information focuses on education, child development, disabilities, health care, effective home-school partnerships, fatherhood, Early Intervention, transition planning, violence prevention, literacy, basic rights, special education law and more. In addition to offering families with children guidance, referrals, training and support, RIPIN maintains a lending library of books and videos and a website full of helpful links and resources for helping all children reach their full potential.

175 Main Street

Pawtucket, RI 02860

Phone: 401-727-4144 or 800-464-3399 (toll free in RI only)

Fax: 401-727-4040

[ripin@ripin.org](mailto:ripin@ripin.org)

[www.ripin.org](http://www.ripin.org)

### Parent Support Network of Rhode Island (PSN)

This program is a statewide organization of families supporting families that have children who are at risk or have behavioral and/or emotional challenges. Support is provided that considers a family's background and values. The Parent Support Network (PSN) provides support groups, telephone support, educational events, one-to-one assistance with advocacy and literature about education, mental health, and parenting a child with special emotional or behavioral needs.

400 Warwick Avenue

Warwick, RI 02886

Phone: 401-467-6855 or 800-483-8844

### Adoption Rhode Island

500 Prospect Street

Pawtucket, RI 02860

Phone: 401-724-1910

[adoptionri.org](http://adoptionri.org)

### Amputee Peer Support Group

Sponsored by OSCIL

Susan Eleoff

Phone: 401-738-1013

TDD: 401-738-1015

### Bipolar/Mental Health Support Group

For families of children with mental health concerns. Meetings held on the first and third Tuesday of every month.

Childcare is available if registered early.

Chris Brown at 401-432-1205

Linda Remarski at 401-658-2552

Cheryl Santos at 401-941-1891

Bradley Hospital

1011 Veterans Memorial Parkway

East Providence, RI

### Bradley Hospital

1011 Veterans Memorial Parkway

East Providence, RI

Phone: 401-434-3400

### Brain Injury Association of RI

Support groups for head injury survivors and their families.

Michelle Branch

Phone: 401-725-2360

### BrainTalk Communities: Online Patient Support Groups for Neurology

[neuro-mancer.mgh.harvard.edu/cgi-bin/Ultimate.cgi](http://neuro-mancer.mgh.harvard.edu/cgi-bin/Ultimate.cgi)

### Directory of State Protection and Advocacy Agencies

Trace Center @ College of Engineering, University of Wisconsin - Madison

[trace.wisc.edu/docs/quick\\_sheets](http://trace.wisc.edu/docs/quick_sheets)

### Exceptional Parent

[www.eparent.com](http://www.eparent.com)

**Family Village**

A global community that integrates information, resources, and communication opportunities on the Internet for persons with cognitive and other disabilities, for their families, and for those that provide them services and support.  
[www.familyvillage.wisc.edu](http://www.familyvillage.wisc.edu)

**Groden Center**

88 Mount Hope Avenue  
Providence, RI 02906  
Phone: 401-274-6310

**Multiple Sclerosis Support and Outreach Groups**

Sponsored by National Multiple Sclerosis Society, RI Chapter.

Gwen Norwood Reeve  
Phone: 401-738-8383

**National Information Center for Children and Youth with Disabilities**

PO Box 1492  
Washington, DC 20013-1492  
Phone/TTY: 202-884-8400 or 800-695-0285  
Fax: 202-884-8441  
[nichey@aetd.org](mailto:nichey@aetd.org)  
[www.nichcy.org](http://www.nichcy.org)

**Online Asperger Syndrome Information and Support (OASIS)**

[www.udel.edu/bkirby/asperger](http://www.udel.edu/bkirby/asperger)

**OSCIL Drop-In Center**

Social and recreational group for ages 13 to 30. Registration required. Meetings are monthly.

Ann Marie Breslin  
Phone: 401-738-1013  
TDD: 401-438-1015  
[www.oscil.org](http://www.oscil.org)

**Parent Information Center  
(Northeast Regional Center)**

PO Box 2405  
Concord, NH 03302-2405  
Phone: 603-224-7005  
Fax: 603-224-4379  
[picnh@aol.com](mailto:picnh@aol.com)

**Parent Teacher Association (PTA)**

RIC Campus-Building #6  
600 Mt. Pleasant Avenue  
Providence, RI 02908  
Phone: 401-272-6405

**Parents Exchange of Jewish Family Service**

229 Waterman Street  
Providence, RI 02906  
Phone: 401-331-KIDS

**Rehabilitation Hospital of RI**

Support group for those coping with head injuries.  
Contact  
Michelle Branch  
Phone: 401-766-0800 x5513

**Rhode Island Parents' Paper**

[www.parenthoodweb.com](http://www.parenthoodweb.com)

**RI ARC**

99 Bald Hill Road  
Cranston, RI 02920  
Phone: 401-463-9191

**Sargent Center**

Sargent Rehabilitation Center  
800 Quaker Lane  
Warwick, RI  
Phone: 401-783-9661

**Self-Help for Hard of Hearing People (SHHH)**

Myron Waldman  
Sargent Rehabilitation Center  
800 Quaker Lane  
Warwick, RI  
Phone: 401-783-9661

**Sibling Support Group**

Sponsored by AMI CAN of RI, Bradley Hospital, and the Mental Health Association of RI  
Phone: 401-331-3060

**Support Group for Parents of Children with Neuromuscular Diseases**

Sponsored by Muscular Dystrophy Association. Meetings held monthly at Rhode Island Hospital.  
Mary Leeman  
Phone: 401-823-5260

**Support Group for People with Seizure Disorders**

Janet Mullen  
Phone: 401-725-1966

**United Way Helpline (Travelers Aid)**

177 Union Street  
Providence, RI  
Phone: 401-351-6500

**Young Stroke Support Group**

Meetings held on first Wednesday of every month.  
Janice B. Hulme  
1160 Post Road  
Warwick, RI  
Phone: 401-781-4441

## **Legal Assistance/Protection, Information, and Advocacy Agencies**

### **Administration on Developmental Disabilities (ADD)**

Administration for Children and Families, U.S. Department of Health and Human Services

The Administration on Developmental Disabilities (ADD) is the federal agency that administers the four programs authorized by the Developmental Disabilities Act. These programs include the Developmental Disabilities Council's Protection and Advocacy Systems, University Affiliated Programs, and Projects of National Significance.

370 L'Enfant Promenade, SW

Mail Stop: HHH F

Washington, DC 20201

Phone: 202-690-6590

[www.acf.dhhs.gov/programs/add](http://www.acf.dhhs.gov/programs/add)

[add@acf.dhhs.gov](mailto:add@acf.dhhs.gov)

### **Advocates in Action (statewide self-advocacy group)**

Deb Griffin-Kney and Kevin McHale

PO Box 41528

Providence, RI 02940-1528

Phone: 401-785-2028

TDD: 800-745-5555

[www.aina-ri.org](http://www.aina-ri.org)

### **Commission for Human Rights**

The objective of the Commission for Human Rights is to enforce anti-discrimination laws mandated by state and federal law.

John Susa, Chair

10 Abbot Park Place

Providence, RI 02903

Phone: 401-222-2661

Fax: 401-22-2616

TDD: 401-222-2664

### **Disability Rights Activist**

[www.disrights.org](http://www.disrights.org)

### **Justice For All**

[www.jfanow.org](http://www.jfanow.org)

### **National Association of Protection and Advocacy Systems (NAPAS)**

NAPAS represents federally mandated programs that protect the rights of persons with disabilities.

900 2nd Street, NE, Suite 211

Washington, DC 20002

Phone: 202-408-9514

Fax: 202-408-9520

[NAPAS@earthlink.net](mailto:NAPAS@earthlink.net)

[www.protectionandadvocacy.com](http://www.protectionandadvocacy.com)

### **Rhode Island Disability Law Center, Inc.**

RIDLc is a non-profit organization that provides free legal assistance to persons with disabilities and distributes information on the rights of people with disabilities.

Raymond L. Bandusky, Executive Director

349 Eddy Street

Providence, RI 02903

Phone: 401-831-3150 or 800-692-7443

TDD: 401-831-5335

Fax: 401-274-5568

[www.ridlc.org](http://www.ridlc.org)

# Housing

## **Rhode Island Housing and Mortgage Finance Company**

As the state's principal housing agency, we help low- and moderate-income Rhode Islanders find houses and apartments they can afford. Get a low-interest loan to buy a house. Find an apartment you can afford. Get money to repair your home or remove hazardous material such as lead paint and asbestos. We even help developers build affordable apartments. Our mission is to assist Rhode Islanders who, by reason of income, special need or circumstance, are unable to fairly obtain and sustain a healthy, affordable home. More than just a physical structure, a home includes the people within and the community around. We're a self-supporting agency, which receives no state tax dollars. Since 1973, we have helped 175,000 Rhode Islanders find houses and apartments they can afford.

44 Washington Street  
Providence, RI 02903-1721  
Phone: 401-757-5566  
TDD: 401-427-9799  
[www.rihousing.com](http://www.rihousing.com)

## **Housing Resources Commission**

The Rhode Island Housing Resources Commission (HRC) was created by legislation in 1998 to be the planning and policy, standards and programs agency for housing issues. The Commission's purpose is to ensure that all Rhode Islanders have access to safe and affordable housing. We are a 27 member Commission, representing a wide range of constituents, from government to providers to advocates.

41 Eddy Street  
Providence, RI 02906  
Phone: 401-450-1350  
Fax: 401-450-1394  
[www.hrc.state.ri.us](http://www.hrc.state.ri.us)

## Other Resources for Families

### Women, Infants, Children Program (WIC)

This health and nutrition program promotes health and development through good nutrition. The program is for pregnant and breastfeeding women and children up to age 5 who are at nutritional risk. Families may apply to the program if their income is at or below 185 percent of the federal poverty level. Additionally, families who currently receive benefits from Medical Assistance, Katie Beckett, RIte Care, Family Independence Program (FIP), and the Food Stamps Program may also apply for WIC benefits. Immigrant women and children may also be eligible. (Includes individuals with or without documented status).

Rhode Island Department of Health; Women, Infants, Children Program  
3 Capitol Hill, Room 302  
Providence, RI 02908-5097  
Phone: 401-222-4604  
Fax: 401-222-1442

### WIC Clinics in Rhode Island

*Chad Brown Health Center*  
285A Chad Brown Street  
Chad Brown Health Center  
285A Chad Brown Street  
Providence 02908  
401-831-0020

*Women and Infants Hospital*  
2 Dudley Street  
Providence 02905-2401  
401-274-1122 x2798

*Allen Berry Health Center*  
202 Prairie Avenue  
Providence 02907  
401-444-0570

*Capitol Hill Health Center*  
40 Candace Street  
Providence 02908  
401-444-0550

*Central Health Center*  
239 Cranston Street  
Providence 02907  
401-444-0580

*Fox Point Health Center*  
550 Wickenden Street  
Providence 02903  
401-444-0530

*Olneyville Health Center*  
100 Curtis Street  
Providence 02909  
401-444-0540

*Blackstone Valley Community Health Center*  
9 Chestnut Street  
Central Falls 02863  
401-724-7134

*John J. Cunningham Health Center*  
42 Park Place  
Pawtucket 02860  
401-722-0082

*Thundermist Health Association*  
191 Social Street, 9th Floor  
Woonsocket 02895  
401-767-4160

*Thundermist Health Association  
(Northwest)*  
The Bridgeway  
Pascoag, 02859  
401-568-7661

*Tri-Town Health Center*  
1126 Hartford Avenue  
Johnston 02919  
401-351-2750 x132

*Family Health Services Center*  
1090 Cranston Street  
Cranston 02920  
401-946-4650

*Ferris Community Health Center*  
821 West Shore Road  
Warwick 02889  
401-737-1150

*Warwick CAP, West Warwick Community  
Health Center*  
53 Providence Street  
West Warwick 02893  
401-826-3230

*Wood River Health Services*  
832 Main Street  
Hope Valley 02832  
401-539-2461

*Health Center of South County*  
One River Street  
Wakefield 02879  
401-782-0855

*Health Center of South County (Bayshore)*  
North Kingstown 02852  
401-782-0855

*Newport Community Health Center*  
19 Broadway  
Newport 02840  
401-847-7821

*James F. Silvia Health Center*  
1048 Stafford Road  
Tiverton, RI 02878  
401-625-5197

*East Providence Health Center*  
100 Bullocks Point  
East Providence 02915  
401-437-1007

*East Providence Health Center (Warren)*  
790 Main Street  
Warren 02885  
401-437-1007

*St. Joseph Health Center*  
21 Peace Street  
Providence 02907  
401-456-4045

*Florence Gray Center*  
1 York Street  
Newport 02840



## Family Resource Counselor Program

This program supports community health centers and hospital clinics to enroll families in preventive health and family support programs including Medicaid/RIte Care, Women, Infants, Children (WIC), Food Stamps and the Family Independence Program (FIP). Counselors help families apply for programs and let them know what they may be eligible for. Families can apply at the following locations:

*Bayside Family Health Care*  
North Kingstown  
401-295-9706

*Family Health Services*  
Cranston  
401-943-1981

*Thundermist Health Associates*  
Woonsocket  
401-767-5444 x3476

*Health Center of South County*  
Wakefield  
401-783-0523

*Family Health Services*  
Coventry  
401-828-5335

*Tri-Town Health Center*  
Johnston  
401-351-2750

*Blackstone Valley Community Health Care*  
Pawtucket  
401-722-0081

*Hasbro Children's Hospital/RI Hospital*  
Providence  
401-444-4000

*Women and Infants Hospital*  
Providence  
401-274-1122 x2778

*Memorial Hospital*  
Pawtucket  
401-729-2634

*Northwest Health Center*  
Harmony  
401-568-7661 x13

*Wood River Health Services*  
Wood River  
401-539-2461

*Chad Brown Health Center*  
Providence  
401-274-6339

*St. Joseph's Health Services*  
Providence  
401-456-4029

*Providence Community Health Centers*  
(see WIC list for this list)

*New Visions for Newport County*  
Newport  
401-847-7821

*Self Help/East Bay Family Health Care*  
East Providence  
401-437-5105

## Family Fun

This is just a small sampling of what you can do with your family. Check your local community listings for events activities in your area for low cost or free fun.

### The Enchanted Forest of RI

Special services include: accessible restrooms, drinking fountains, telephones, restaurants, rides and attractions, theaters, and parking; guide dogs permitted; first aid station; and special ticket rates. This park appeals to younger children.  
Route 3  
Hope Valley, RI 02832  
Phone: 401-539-7711

### Canobie Lake Park

PO Box 190  
Salem, NH 03079-0190  
Phone: 603-893-3506  
[www.canobie.com](http://www.canobie.com)

### FantasyLand

1300 Fall River Avenue  
Seekonk, MA 02771

### Six Flags Amusement Parks

[www.sixflags.com](http://www.sixflags.com)

### Spooky World

All rides are accessible, it received a commendation from the Surgeon General for their accessibility efforts.  
100 River Road  
Berlin, MA 01503-1647  
Phone: 978-838-0200

### Walt Disney Attractions, Inc.

PO Box 10500  
Lake Buena Vista, FL 32830  
Phone: 800-4DISNEY  
[www.disney.com](http://www.disney.com)

### Family Fun

Monthly magazine loaded with activities for all ages.  
[www.familyfun.com](http://www.familyfun.com)



## Elected Government Officials

Information on state representatives and other elected officials is available on the website of the Secretary of State at [www.state.ri.us](http://www.state.ri.us).

### United States House of Representatives

*Patrick Kennedy (D-First District)*

Washington office:  
407 Cannon House Office Building  
US House of Representatives  
Washington, DC 20515  
Phone: 401-225-4911 or 800-392-5772 (in Rhode Island)  
Fax: 202-225-3290

Rhode Island office:  
249 Roosevelt Avenue, Suite 200  
Pawtucket, RI 02860  
Phone: 401-729-5600  
Fax: 401-729-5608  
[patrick.kennedy@mail.house.gov](mailto:patrick.kennedy@mail.house.gov)  
[www.house.gov/patrickkennedy/contact.html](http://www.house.gov/patrickkennedy/contact.html)

*James Langevin (D-Second District)*

Washington office:  
109 Cannon House Office Building  
US House of Representatives  
Washington, DC 20515  
Phone: 202-225-2735

Rhode Island office:  
300 Centerville Road, Suite 200  
Warwick, RI 02886  
Phone: 401-732-9400 or 401-453-5294  
Fax: 401-737-2982

### United States Senators

*Lincoln Chafee (R)*

Washington office:  
United States Senate  
505 Dirksen Building  
Washington, DC 20510  
Phone: 202-224-2921 or 800-662-5188 (in Rhode Island)  
TTY: 202-224-7746  
E-mail: [senator\\_chafee.senate.gov](mailto:senator_chafee.senate.gov)  
Website: [www.senate.gov/~chafee/](http://www.senate.gov/~chafee/)

Rhode Island office:  
170 Westminster Street, Suite 1100  
Providence, RI 02903  
Phone: 401-453-5294

*Jack Reed (D)*

Washington office:  
United States Senate  
320 Hart Senate Office Building  
Washington, DC 20510-3901  
Phone: 202-224-4642  
Fax: 202-224-4680  
Email: [jack@reed.senate.gov](mailto:jack@reed.senate.gov)  
Website: [www.senate.gov/~reed](http://www.senate.gov/~reed)

Rhode Island office:  
201 Hillside Road, Suite 200  
Cranston, RI 02920-5602  
Phone: 401-943-3100 or 800-284-4200  
TDD: 800-745-5555  
Fax: 401-464-6837

### Governor

*Governor Donald L. Carcieri*

222 State House  
Providence, RI 02903  
Phone: 401-222-2080  
[rigov@gov.state.ri.us](mailto:rigov@gov.state.ri.us)  
[www.governor.state.ri.us](http://www.governor.state.ri.us)

## State Departments, Agencies, and Commissions

### *Governor's Commission on Disabilities*

John O. Pastore Center (formerly the Howard Center)

Executive Secretary: Bob Cooper

41 Cherry Dale Court

Cranston, RI 02920-3049

Phone: 401-462-0100

TTY: 401-462-0101

Fax: 401-462-0106

[disabilities@gcd.state.ri.us](mailto:disabilities@gcd.state.ri.us)

[www.gcd.state.ri.us](http://www.gcd.state.ri.us)

### *Rhode Island General Assembly*

[www.rilin.state.ri.us](http://www.rilin.state.ri.us)

### *Rhode Island Office of Rehabilitation Services*

[www.ors.state.ri.us](http://www.ors.state.ri.us)

### *Rhode Island Department of Children, Youth, and Families*

[www.dcyf.state.ri.us](http://www.dcyf.state.ri.us)

### *Rhode Island Department of Education*

[www.ridoe.net](http://www.ridoe.net)

### *Rhode Island State Department of Health*

[www.healthri.org](http://www.healthri.org)

### *Rhode Island Department of Human Services*

Phone: 888-DHS-3322

[www.dhs.state.ri.us](http://www.dhs.state.ri.us)

### *Rhode Island Department of Mental Health, Retardation, and Hospitals*

[www.mhrh.state.ri.us](http://www.mhrh.state.ri.us)

### *Rhode Island Government Owner's Manual (free of charge)*

401-222-2357

[www.state.ri.us/rimanual](http://www.state.ri.us/rimanual)

### *Child Care Subsidies, Department of Human Services*

Phone: 888-DHS-3322

[www.dhs.state.ri.us](http://www.dhs.state.ri.us)

### *Child Support Enforcement Office, Department of Human Services*

Phone: 800-638-KIDS

[www.dhs.state.ri.us](http://www.dhs.state.ri.us)

### *Electronic Benefit Transfer (EBT)*

Customer Service

Department of Human Services

Phone: 888-979-9939

### *Family Independence Program, Department of Human Services*

Phone: 888-DHS-3322

[www.dhs.state.ri.us](http://www.dhs.state.ri.us)

### *Food Stamps, Department of Human Services*

Phone: 800-662-5018

[www.dhs.state.ri.us](http://www.dhs.state.ri.us)

### *Earned Income Tax Credit Information, Internal Revenue Service*

Phone: 800-829-1040

## Political Information

### *Congress*

[congress.org](http://congress.org)

### *Federal Election Commission - The National*

*Mail Voter Registration Form*

[www.fec.gov/votregis/vr.htm](http://www.fec.gov/votregis/vr.htm)

### *Project Vote Smart - A Voter's Self-Defense System*

[www.vote-smart.org](http://www.vote-smart.org)

### *CanDo.com*

[cando.com](http://cando.com)

### *I-CAN Online*

[www.icanonline.net](http://www.icanonline.net)

### *WEmedia*

[www.wemedia.com](http://www.wemedia.com)

## Disability Information

*Ability to Independence - The VISUAL  
disAbility Expo for the disAbled*  
Website: [remote-ability.com](http://remote-ability.com)

*California State University, Northridge-  
Center On Disabilities*  
[www.csun.edu/cod](http://www.csun.edu/cod)

*CDC-National Center for Birth Defects and  
Developmental Disabilities*  
[www.cdc.gov/ncbddd](http://www.cdc.gov/ncbddd)

*Cornucopia of Disability Information*  
[codi.buffalo.edu](http://codi.buffalo.edu)

*Creativity Explored*  
[www.creativityexplored.org](http://www.creativityexplored.org)

*Dealing with Disability*  
[www.metlife.com/index](http://www.metlife.com/index)

*Disability News Service*  
[www.disabilitynews.com](http://www.disabilitynews.com)

*Disability News Ticker*  
[www.abilityinfo.com/ticker.html](http://www.abilityinfo.com/ticker.html)

*Films Involving Disabilities*  
[www.disabilityfilms.co.uk](http://www.disabilityfilms.co.uk)

*GARAVENTA (Canada) LTD - Accessibility  
Solutions*  
[www.garaventa.com](http://www.garaventa.com)

*Health-Helper - Brain Injury, Concussion  
and Health Resources*  
[www.health-helper.com](http://www.health-helper.com)

*Integrated Arts-Home for Creative  
Expression*  
[www.icomm.ca/iarts](http://www.icomm.ca/iarts)

*Internet Resources for Special Children  
(IRSC)*  
[www.irsc.org](http://www.irsc.org)

*National Institute of Art & Disability*  
[www.niadart.org](http://www.niadart.org)

*National Library Service for the Blind and  
Physically Handicapped*  
[www.lcweb.loc.gov/nls](http://www.lcweb.loc.gov/nls)

*On A Roll - Talk Radio on Life and  
Disability*  
[www.onarollradio.com](http://www.onarollradio.com)

*rehabNET - Resource on Disability and  
Medical Rehabilitation*  
[www.rehabnet.com/index.html](http://www.rehabnet.com/index.html)

*Through the Looking Glass*  
[www.lookingglass.org](http://www.lookingglass.org)

*Trace Research and Development Center*  
[www.trace.wisc.edu](http://www.trace.wisc.edu)

# Feedback Form

We would like to know your thoughts about this guide, and suggestions you may have for inclusion in future updates. Please use the space below to share your comments or to report corrections. We especially appreciate comments about how you have or will use this information to help your child(ren) and/or yourself. Thank you in advance.

## Comments

---

---

---

---

---

---

---

---

---

## Corrections

Page: \_\_\_\_\_  
Entry: \_\_\_\_\_  
Correct information:

Page: \_\_\_\_\_  
Entry: \_\_\_\_\_  
Correct information:

Page: \_\_\_\_\_  
Entry: \_\_\_\_\_  
Correct information:

---

---

---

If you would like to receive periodic updates of this guide, please complete the following information.

Name: \_\_\_\_\_

Agency Affiliation (if appropriate): \_\_\_\_\_

Title (if appropriate): \_\_\_\_\_

Address: \_\_\_\_\_

City/State/Zip: \_\_\_\_\_

Telephone: \_\_\_\_\_

TTY: \_\_\_\_\_

Email: \_\_\_\_\_

I am a:            ☐ Parent of a child with a disability    ☐ Individual with a disability  
(Check all        ☐ Disability-related service provider    ☐ Teacher/educator  
that apply)      ☐ Other (describe) \_\_\_\_\_

Contact Family Voices with your feedback by returning this form to:

Family Voices at the Rhode Island Parent Information Network  
175 Main Street  
Pawtucket, RI 02860  
Fax: 401-727-4040  
Email: [familyvoices@ripin.org](mailto:familyvoices@ripin.org)

# Glossary

## Health Care Definitions

**ACUTE CARE:** Medical services provided after an accident or for a disease, usually for a short time period.

**AMBULATORY CARE:** Medical care provided on an outpatient (non-hospital) basis.

**ANESTHETIST:** Specialist in reducing pain during surgery. This is done by giving the patient anesthesia (a powerful painkiller).

**ASSISTIVE TECHNOLOGY DEVICE:** Any item, piece of equipment, or product system that is used to increase, maintain, or improve the daily living of a child with a disability.

**AUDIOLOGIST:** A hearing specialist who can diagnosis and help a person with a hearing impairment that cannot be improved by medication or surgical therapy.

**CARDIOLOGIST:** Specialist of the heart and blood vessels.

**CARE COORDINATION:** The process of having all care needs coordinated by one person.

**CASE MANAGEMENT PROGRAM:** A program now offered by many insurance companies, particularly for individuals who require high-cost care or have a chronic condition. Under the program, a case manager is assigned to manage a person's health needs. Contact your health insurance plan to find out if you are eligible and how it works.

**CHILD WITH A DISABILITY:** A child with mental retardation, hearing loss (including deafness), speech or language impairments, loss of eyesight (including blindness), serious emotional disturbance, physical impairments, autism, traumatic brain injury, other health impairments, or specific learning disabilities that need special health care or education.

**CHILDREN WITH SPECIAL HEALTH CARE NEEDS:** Children who have, or are at increased risk of chronic physical, developmental, behavioral, or emotional conditions. Children with special health care needs receive more health care and services than other children.

**CHRONIC CARE:** Continuous care required over a period of time for people who have long-term disabilities or health problems.

**CLINICIAN:** All types of medical professionals who care for patients, including doctors or physicians, nurses, physician's assistants, therapists, etc.

**COLLABORATIVE CARE:** Working with your child's doctor to make treatment choices that are best for your child.

**CONTINUITY OF CARE:** When the care of a patient is continuous (without interruption) from the onset of illness until its completion. Multiple forms of care, such as health care and social services, may be provided to the patient.

**CRITICAL CARE:** Management of all aspects of a critically ill patient, who is usually in the Intensive Care Unit.

**DERMATOLOGIST:** Specialist of the skin and skin disorders.

**DURABLE MEDICAL EQUIPMENT:** Necessary medical equipment that is not disposable; for example, leg braces, wheelchairs, walkers, ventilators, hearing aids, commodes, etc.

**EARLY INTERVENTION:** A program that serves children younger than three years old with developmental delays and their families. The program provides evaluation of your child's development; in-home support; links to the community; and services to help your child.

**EARLY PERIODIC SCREENING DIAGNOSIS AND TREATMENT:** A program that requires that Medicaid eligible children be screened for medical, dental, vision, mental health, and developmental problems. If any problems are identified, the child is eligible to receive certain necessary treatments regardless of whether those treatments are part of your state's Medicaid plan.

**EMERGENCY CARE:** Immediate care that is necessary when a child has a condition, illness, or injury that is life-threatening or that would significantly harm his or her health.

**ENDOCRINOLOGIST:** Specialist of the organs that produce hormones, such as ovaries and testes.

**ENT (EAR, NOSE, AND THROAT):** A specialist who provides medical and surgical treatment of the head and neck, including the ears, nose, and throat.

**FAMILY-CENTERED CARE:** Health care that is based on the concerns, priorities and resources of the family. Communication between parents and medical providers is encouraged.

**GASTROENTEROLOGIST:** Specialist of the stomach, intestines, and related organs.

**GENERIC MEDICINES:** Medications that do not have a brand name, but contain the same ingredients as brand name medications. Usually, generic medicines are less expensive.

**GENETICIST:** Specialist of how traits of parents (including certain diseases) are given to their children.

**HEMATOLOGIST:** Specialist of the blood.

#### **HOME AND COMMUNITY BASED SERVICES WAIVERS AND MEDICAID PLAN**

**AMENDMENTS:** This program allows some children with special needs whose parents are over income limits for Medicaid to qualify for Medicaid benefits.

**HOSPICE SERVICES:** Care for people with terminal illnesses and their families.

#### **INDIVIDUALS WITH DISABILITIES**

**EDUCATION ACT:** A federal law that guarantees all children with disabilities access to free and appropriate public education.

**INPATIENT CARE:** When a patient is admitted into a hospital and receives care within the hospital. A patient can also receive "outpatient" care in a hospital's emergency room or ambulatory care center.

**INTERNIST:** Specialist of diseases of organs in the chest, abdomen, or head.

**MATERNAL AND CHILD HEALTH BLOCK**

**GRANT:** A federal grant for providing care and services to children and mothers. A certain amount of these funds must be used for children with special health care needs.

**MEDICAID:** Funded jointly by state and federal monies, this public program provides health care benefits for those who meet certain income requirements. In some cases, income may be waived. When Medicaid is paying for services, the providers must be approved Medicaid providers.

**NEONATOLOGIST:** Specialist of the care and treatment of newborn infants.

**NEPHROLOGIST:** Specialist of the diagnosis and treatment of kidney disorders.

**NEUROLOGIST:** Specialist of the nervous system. The nervous system includes the brain and spinal cord.

**NEUROSURGERY:** Surgery of the brain and spinal cord.

**OBSTETRICIAN:** Specialist of pregnancy, labor, and the period right after childbirth.

**OCCUPATIONAL THERAPY:** Therapy that aims to increase independence or prevent further disability through work and play activities.

**ONCOLOGIST:** Specialist of the diagnosis and treatment of tumors and cancer.

**OPHTHALMOLOGIST:** Specialist of the eyes.

**OPTOMETRIST:** Specialist that diagnoses vision problems and writes prescriptions for corrective lenses to preserve or improve eyesight.

**ORTHOPEDIC SURGEON:** Specialist of surgical prevention and correction of deformities of muscles and bones.

**ORTHOTIC DEVICE:** Braces that support weak or injured joints and muscles.

**PALLIATIVE CARE:** Care that improves the quality of life of patients facing life-threatening illness and their families . Palliative care focuses on the prevention and relief of pain by means of early identification, assessment, and treatment. It also focuses on prevention and relief of pain and other physical, psychosocial, and spiritual problems.

**PEDIATRICIAN:** Specialist of the development and care of children and treatment of childhood diseases.

**PHYSICAL THERAPIST:** A specialist who uses exercise, temperature, electricity, ultrasound, and massage to improve physical function of a patient and prevent disability.

**PLASTIC SURGERY:** Reconstruction, correction, or improvement in the shape and appearance of body structures by surgery.

**PREVENTIVE CARE:** Medical services that try to reduce the chances of illness, injury or other conditions before they actually occur. This contrasts with acute care, which is given after the condition has occurred.

**PRIMARY CARE:** Routine medical care that is usually provided in a doctor's office or clinic.

**PRIMARY CARE PHYSICIAN:** Physicians who are pediatricians, family physicians, internists, or general practitioners.

**PROSTHETIC:** An artificial limb.

**PROVIDER:** A hospital, skilled nursing facility, outpatient surgical facility, physician, practitioner or other individual or organization that is licensed to provide medical services, therapy, or treatment.

**PSYCHIATRIST:** Specialist in the diagnosis, treatment, and prevention of mental disorders. A psychiatrist may prescribe medication.

**PSYCHOLOGIST:** Specialist dealing with normal and abnormal mental processes and their effects upon behavior.

**PULMONARY DISEASES:** Diseases of the lungs.

**RADIOLOGIST:** Specialist in the diagnosis and treatment of disease through x-rays.

**RESPIRATORY THERAPY:** Treatment to help the lungs work properly.

**RHEUMATOLOGIST:** Specialist in the diagnosis and treatment of swelling and pain in muscles or joints.

**SECONDARY CARE:** Medical care provided by medical specialists that usually requires a referral from a primary care physician.

**SPECIALIST:** A medical professional whose practice is limited to a particular branch of medicine, surgery, or research (examples: allergist, physical therapist, etc.).

**SPEECH THERAPIST:** Specialist using techniques to correct disorders of speech, language, swallowing/feeding, and voice.

**SUPPLEMENTAL SECURITY INCOME:** A federal program that provides cash and access to Medicaid (in most states) for children who have specific disabilities or chronic illnesses. To be eligible, parents must meet income criteria.

**TERTIARY CARE:** Very specialized medical care and services, usually provided in hospitals by highly trained specialists using the most advanced medical technology.

**URGENT CARE:** Care provided when a patient has an illness that is not life-threatening but that requires immediate attention.

**UROLOGIST:** Specialist of the urinary tract in both males and females, and the genital tract in males.



# Helpful acronyms

## for Families of Children with Special Needs

### A

<b>ADHD</b>	Attention Deficit/Hyperactivity Disorder
<b>ARC</b>	Association for Retarded Citizens
<b>ASD</b>	Autism Spectrum Disorder
<b>ASRI</b>	Autism Society of Rhode Island
<b>AT</b>	Assistive Technology

### C

<b>CDC</b>	Child Development Center (also Centers for Disease Control and Prevention)
<b>CEDARR</b>	Comprehensive Evaluation, Diagnosis, Assessment, Referral and Re-evaluation
<b>CF</b>	Cystic Fibrosis
<b>CHIP</b>	Children's Health Insurance Program
<b>CNA</b>	Certified Nurse Assistant
<b>COZ</b>	Child Opportunity Zone
<b>CP</b>	Cerebral Palsy
<b>CSHCN</b>	Children with Special Health Care Needs

### D

<b>DCYF</b>	Department of Children, Youths and Families
<b>DDS</b>	Disability Determination Services
<b>DHS</b>	Department of Human Services
<b>DOE</b>	Department of Education
<b>DOH</b>	Department of Health
<b>DSSRI</b>	Down Syndrome Society of Rhode Island

### E

<b>EFA</b>	Epilepsy Foundation of America
<b>EI</b>	Early Intervention

### F

<b>FAS</b>	Fetal Alcohol Syndrome
<b>FIP</b>	Family Independence Program
<b>FOP</b>	Family Outreach Program
<b>FRC</b>	Family Resource Counselor

### I

<b>IDEA</b>	Individuals with Disabilities Education Act
<b>IEP</b>	Individualized Education Program
<b>IFSP</b>	Individualized Family Service Plan

L		P	
<b>LCSW</b>	Licensed Clinical Social Worker	<b>PA</b>	Licensed Physician Assistant
<b>LEA</b>	Local Education Agencies	<b>PAT</b>	Parents As Teachers
<b>LICSW</b>	Licensed Independent Clinical Social Worker	<b>PCP</b>	Primary Care Provider
<b>LMHC</b>	Licensed Mental Health Counselor	<b>PDD</b>	Pervasive Developmental Disorder
M		<b>PNP</b>	Professional Nurse Practitioner
<b>MCH</b>	Maternal and Child Health	<b>PSN</b>	Parent Support Network
<b>MD</b>	Medical Doctor (also Muscular Dystrophy)	<b>PT</b>	Physical Therapy (also Physical Therapist)
<b>MHRH</b>	Department of Mental Health, Retardation, and Hospitals	R	
<b>MS</b>	Multiple Sclerosis	<b>RIAD</b>	Rhode Island Association of the Deaf
N		<b>RIDE</b>	Rhode Island Department of Education
<b>NICU</b>	Neonatal Intensive Care Unit	<b>RIHAP</b>	Rhode Island Hearing Assessment Program
<b>NP</b>	Nurse Practitioner	<b>RIPIN</b>	Rhode Island Parent Information Network
O		<b>RN</b>	Registered Nurse
<b>OSERS</b>	Office of Special Education and Rehabilitation Services	S	
<b>OT</b>	Occupational Therapy	<b>SCHIP</b>	State Children's Health Insurance Program
		<b>SILC</b>	Statewide Independent Living Council
		<b>SLP</b>	Speech and Language Pathologist
		<b>SPED</b>	Special Education Department
		<b>SSDI</b>	Social Security Disabilities Insurance
		<b>SSI</b>	Supplemental Security Income

+

+

+

## T

---

<b>TBI</b>	Traumatic Brain Injury
<b>TBSCI</b>	Traumatic Brain and Spinal Cord Injury Program
<b>TCYC</b>	Therapeutic Child and Youth Care
<b>TTD or TTY</b>	Teletype for the Deaf

## U

---

<b>UCPRI</b>	United Cerebral Palsy of Rhode Island
--------------	---------------------------------------

## V

---

<b>VIP-RI</b>	Vulnerable Infants Programs of Rhode Island
<b>VNA</b>	Visiting Nurse Association
<b>VNS</b>	Visiting Nurse Services

## W

---

<b>WIC</b>	Women, Infants, Children Supplemental Nutrition Program
------------	---



# Acknowledgements

The Rhode Island Department of Health would like to recognize the various organizations and groups that contributed to the creation of the *Complete Care Notebook*. We thank Family Voices and the Rhode Island Parent Information Network for their contribution and input. A special thank you to the parents of children with special needs whose time and effort was invaluable.

Finally, the Rhode Island Department of Health would like to recognize Brown University's student interns, Children's Hospital and Regional Medical Center of Seattle, Washington, New England SERVE, the University of Illinois at Chicago, and the Washington State Department of Health for their contribution of time and materials.

